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ABSTRACT

This first symposium of the Work Group on American Indian Research and Program Evaluation Methodology (AIRPEM) explored American Indian and Alaska Native cultural considerations in relation to "best practices" in research and program evaluation. These cultural considerations include the importance of tribal consultation on research projects and the need for attention to Native cultural factors in general and to the great cultural diversity of Indian nations. Following an introductory section, part 2 contains five papers: "A Brief History of and Future Considerations for Research in American Indian and Alaska Native Communities" (Jamie D. Davis, Kelly Keemer); "Research in Indian Country: Challenges and Changes" (Walter Hillabrant); "Cultural Competence Approaches to Evaluation in Tribal Communities" (Paulette Running Wolf, Robin Soler, Brigitte Manteuffel, Diane Sondheimer, Rolando L. Santiago, Jill Shepard Erickson); "Community-Based Research and American Indians with Disabilities: Learning Together Methods That Work" (Catherine A. Marshall, Sharon R. Johnson, Elizabeth Kendall, Howard Busby, Robert Schacht, Calvin Hill); and "Learning from and Working with Yup'ik Professionals" (Jennifer Olson, Philip D. Olson, Teresa Pangaea, Katherine W. Sterling, Lenea K. M. Pierzchanowski). Part 3 contains cross-cutting critiques and discussions: "Focus on Research Methods" (Spero M. Manson) and related discussion; "Summary and Overview for Day One" (Holly Echo-Hawk); "Focus on Cultural Issues in Research: Developing and Implementing Native American Postcolonial Participatory Action

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Research" (Joseph B. Stone) and related discussion; "Focus on Implications for Policy Practice" (Velma Garcia Mason) and related discussion; and "Final Discussion and Summary Comments" (Holly Echo-Hawk). Appendices contain lists of symposium participants and AIRPEM network participants, a symposium chapter review coding sheet, and "A Model for Conducting Research with American Indian Participants" (Justin D. McDonald). Papers contain references. Author profiles are included. (SV)

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AIRPEM

Work Group on American Indian Research and Program Evaluation Methodology

Symposium on Research and Evaluation Methodology: Lifespan Issues Related to American Indians/Alaska Natives with Disabilities

April 26-27, 2002
Washington, DC

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American Indian Research and
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Editorial Committee

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Justin D. McDonald, Ph.D.

Preface

Research in Indian Country can be, and often is, challenging. Tribes are often sovereign political entities with specific powers of self-governance. This raises issues of protocol and the tribal leaders' acceptance of research agendas. Other challenges faced by researchers are rooted in cultural and language barriers. The American Indian population is highly diverse, speaking about 200 languages and dialects. While there are some beliefs and traditions that are common to many Indian nations, American Indians cannot be perceived as being homogenous.

This monograph has been developed to address alternative and appropriate methods of conducting research with this population. Research with American Indians needs to be academically acceptable in the general research community as well as appropriate culturally and linguistically. In the quest to improve and enhance quality of life for First Nations people, there are environmental, societal, economic, health, and disability issues that need to be addressed, including a need for capacity building throughout Indian Country. Research and program evaluation experiences shared in this monograph are offered as viable methods of impacting these multifaceted issues and problems.

Joyce Y. Caldwell

Rehabilitation Program Specialist
National Institute on Disability and Rehabilitation Research

Acknowledgements

The editorial committee for this monograph acknowledges with appreciation the significant contributions of time by participants who formed the Work Group on American Indian Research and Program Evaluation Methodology (AIRPEM)—colleagues who trusted our process even as we were developing it, beginning with our first meeting in March 2000. From that first meeting, participants in the AIRPEM network assisted in various ways and at various times in planning the *Symposium on Research and Evaluation Methodology: Lifespan Issues Related to American Indians/Alaska Natives with Disabilities*, held April 26-27, 2002, in Washington, DC. We also warmly acknowledge the contributions of our symposium discussants, Dr. Velma Mason, Dr. Spero Manson, and Dr. Joseph Stone, whose thoughtful and thought-provoking critiques of the papers included in this monograph directed our discussions at the symposium and will allow us to develop more fully our thinking and our practice. We are very appreciative of the contribution of the symposium facilitator, Holly Echo-Hawk; her skill in facilitating our work at the symposium was extraordinary, as was her demonstrated commitment to our efforts to better serve American Indians and Alaska Natives with disabilities through research and program evaluation.

On behalf of AIRPEM, we thank the Indian Health Service and the National Institute on Disability and Rehabilitation Research for their financial contributions to the symposium. We also thank the Center for International Rehabilitation Research Information and Exchange (CIRRIE) for making possible the attendance of Dr. Elizabeth Kendall at the symposium. We very much appreciate the staff contributions of the Substance Abuse and Mental Health Services Administration. We acknowledge the contribution of Hélène Flamand, Graduate Assistant, American Indian Rehabilitation Research and Training Center, in researching references. Finally, the editorial committee acknowledges the valued assistance provided to us by editorial consultant, Dr. Barbara Du Bois. The editorial committee itself, however, takes responsibility for any errors or omissions in the monograph.

Part I
Introductions

Introduction to the Monograph

Editorial Committee

Jamie D. Davis, Ph.D.
Jill Shepard Erickson, M.S.W., A.C.S.W.
Sharon R. Johnson, B.A., CRC
Catherine A. Marshall, Ph.D., CRC
Paulette Running Wolf, Ph.D.
Rolando L. Santiago, Ph.D.

The purpose of this monograph is to report on activities of the Work Group on American Indian Research and Program Evaluation Methodology (AIRPEM), including its first symposium, held on terms of collegiality, to address our concerns and share our experiences through critique and discussion of papers prepared for this meeting. Three distinguised American Indian social scientists and social policy experts, Dr. Velma Mason, Dr. Spero Manson, and Dr. Joseph Stone, agreed to critique the papers and join us for our discussions, facilitated by Ms. Holly Echo-Hawk, an organizational behavior and management consultant. The *Symposium on Research and Evaluation Methodology: Lifespan Issues Related to American Indians/Alaska Natives with Disabilities* was held April 26-27, 2002, in Washington, DC; Appendix A contains a list of symposium participants. The informal collegial network now known as AIRPEM evolved in response to the desire to share information and resources among researchers, program evaluators, health and human service professionals, policy makers, and private practitioners who work with American Indians who have disabilities (see Appendix B). Simply stated, we needed each other, we found each other, and we look forward to continuing to learn from each other out of shared interests and concerns. Specifically, the purpose of AIRPEM is to explore, share, and document American Indian cultural considerations in relation to "best practices" in research and program evaluation.

A Brief Summary of Cultural Considerations

AIRPEM participants understand the importance of tribal consultation when proposing research in Indian Country and the importance of conducting research that benefits American Indian communities. We do not support "color blind" research—in other words, we believe that research focusing on the needs of American Indians with disabilities of all age groups is so important that their needs must be specifically addressed in the delivery of health and human services. A history of public data-gathering that is "color blind" has resulted in data through which American Indians can not be identified, nor their needs isolated from those of the majority. AIRPEM participants understand that not only do cultural factors regarding American Indians (considered as one ethnic minority population) affect the research process, but that the diversity among American Indian nations is also to be considered.

Symposium Administration and Support

While persons in the AIRPEM network represent a variety of governmental agencies and private organizations (see Appendices A & B), the American Indian Rehabilitation Research and Training Center (AIRRTC) offered to provide administrative support in organizing the symposium. Administratively based at the Institute for Human Development, Northern Arizona University, in Flagstaff, the AIRRTC has been funded since 1983 by the U.S. Department of Education, Office of Special

Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR). During its almost 20-year history of conducting research nationwide to benefit American Indians and Alaska Natives with disabilities, the AIRRTC has developed considerable knowledge regarding best practices for conducting research that is both sound in design and sensitive to the cultural needs of the individuals, families, and communities with whom and in which we work. The AIRRTC program of research 1) focuses exclusively on an underrepresented and underserved population; 2) focuses particularly on significant social problems associated with American Indians with disabilities, such as unemployment, substance abuse, and being "invisible" in large data sets as well as in social service and health care systems; and 3) focuses not only on improving employment opportunities for American Indians with disabilities but also on alleviating problems of diagnosis of disabling conditions such as FAS/FAE (Fetal Alcohol Syndrome/Fetal Alcohol Effects).

Financial support from the Indian Health Service and from NIDRR ensured that we could hold the symposium and, importantly, that we could produce a proposed monograph based on papers that had been prepared for critique and discussion at the symposium. Significant staff support from the Substance Abuse and Mental Health Services Administration (SAMHSA) ensured that the symposium would offer a successful interchange of experiences. Jill Shepard Erickson, M.S.W., Project Officer at SAMSHA, and Catherine Marshall, Ph.D., Director of Research at the AIRRTC, served as co-coordinators of the AIRPEM symposium.

Symposium Outcomes

From our first planning meeting in March 2000, AIRPEM participants hoped that the symposium would allow participants to solidify the purpose of AIRPEM, that is, the utilization of our collective experiences and knowledge to better serve American Indians with disabilities. We intended to make available a monograph documenting our experience and allowing us a base from which to explore and define future directions in research and program evaluation. On the basis of the prepared papers and invited critiques, our concluding discussion at the symposium led to standards for the monograph which are, we hope, reflected in this document. Ultimately, we hope that through appropriate and accurate needs assessments and program evaluations, communities in Indian Country can see an increase in dollars for community development and problem-solving service delivery. To that end, we hope that this monograph provides examples of research and program evaluation efforts that have appropriately involved American Indians with disabilities. Through this monograph, we share also the critiques of our efforts and some of the discussions that occurred over the day and a half in which we communicated together about our aspirations, positive experiences, struggles, and intentions for future work.

For example, Dr. Spero Manson's comments led us to consider issues relating to the role of the scientist as an advocate in an era when indigenous communities are increasingly taking ownership of the research process, and some of the tensions involved in conducting research in Indian Country. Dr. Joseph Stone asked us to consider the impact of postcolonial stress on the persons whom we are asking to serve as research participants and to reflect deeply upon the implications of colonial and postcolonial trauma for understanding the social, political, spiritual, and health-related experience of contemporary American Indians and Alaska Natives (see Appendix C). Dr. Velma Mason's comments urged us to consider the needs of tribes and reminded us of an obligation to assist with building capacity for tribes to conduct their own research and program evaluation. Discussants also reminded us to remember our history, in particular the Native researchers who first drew attention to cultural issues in research (see, for example, Appendix D).

We also need to acknowledge the history of the disability movement and the attempts of NIDRR-funded researchers such as H. Rutherford Turnbull and Ann Turnbull (1989), who sought to identify "principles of research on people with disabilities and their families" (p. 1) and whose consensus conference noted that "research should be sensitive to cultural, socio-economic, ethnic, life style, and life span pluralisms" (p. 2). Similarly, we need to acknowledge the work of rehabilitation researchers such as Pollard (1992) who, in summarizing ethical principles and practices in conducting research with diverse populations, called to our attention that such considerations apply when conducting research with "members of the sociocultural Deaf community" (p. 88).

Each of the papers prepared for the symposium reflects the contribution of individual or team authors who hoped to learn by sharing and who hoped to participate in improving our science by offering their best efforts for critique. *A Brief History of and Future Considerations for Research in American Indian and Alaska Native Communities* provides a historical and contextual overview of research in Indian Country, tracing the evolution, impact, and implications of attitudes and practices in the social sciences in relation to American Indians and Alaska Natives, bringing us to the opportunities of the present moment. *Research in Indian Country: Challenges and Changes* continues the contextual theme and provides specific examples of factors which must be faced in program evaluation, highlighting particularly questions of ethics in social research in Indian Country. *Cultural Competence Approaches to Evaluation in Tribal Communities* shares the responses of communities to cross-site evaluation efforts in a national evaluation program—responses that highlight not only the diversity in Indian Country but also the creativity with which Native communities are adapting contemporary research and evaluation principles and methods to meet their unique cultural needs, resources, and strengths. *Community-Based Research and American Indians with Disabilities: Learning Together Methods that Work* reflects the almost 20-year history of the AIRRTC's research experience and emphasizes how we can learn not only from the U.S. indigenous cultural experience but also from the experience of indigenous cultures in other countries, underlining the critical significance of culture itself as a primary factor in conceptualizing and carrying out research. *Learning from and Working with Yup'ik Professionals* describes an intervention and program evaluation involving a specific group of Native people, highlighting these Alaska Natives' desire and ability to make use of contemporary program technology and procedures to fulfill their own learning goals.

Some of our symposium discussions had no conclusion; these may be the most important discussions, after all, because they raise questions that others can learn from and creatively address. We hope students will continue the discussions in their classes, that researchers and program evaluators will continue the discussions in their work with American Indian, Alaska Native, and other indigenous communities, and that policy makers will enter the discussions. To that end, we plan to continue communicating and meeting, to hold a second AIRPEM symposium, and to grow the network of AIRPEM participants. As Pollard (1992) concluded, "It is by remaining abreast of ethical and cultural opinions and developments, demonstrating real concern for the issues raised, and employing research practices that are in accordance with one's best informed and reasoned judgments that ethical responsibility is fulfilled" (p. 98).

Thoughts on Future Directions

We intend to stay focused on the intersection of disability and the American Indian and Alaska Native experience. It is important to clarify that we are not looking for one model of research. We respect the needs of individual programs to conduct research and evaluation in accordance with their program objectives. Based on our final discussion at the symposium, specific questions we hope to address and tasks for

AIRPEM participants include:

- How does what we have discussed and learned apply to evidence-based evaluation? How can we identify and contribute to methods that demonstrate successful program outcomes?
- What do we want policy makers to do with this monograph?
- Develop and agree upon standards of research conducted with American Indians who have disabilities—standards that funding agencies would honor when awarding grants.
- Develop a bibliography of publications which have addressed or demonstrated appropriate research and program evaluation methods in Indian Country.
- Identify consumer, professional, and advocacy groups that might be interested in joining our work: for example, National Council on Disability, Inter-tribal Deaf Council, Consortia of Administrators for Native American Rehabilitation (CANAR), National Council on Independent Living (NCIL), Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), The Association of Persons with Severe Handicaps (TASH), National Congress of American Indians (NCAI), and the National Indian Health Board (NIHB).

References

Pollard, R.Q. (1992). Cross-cultural ethics in the conduct of deafness research. *Rehabilitation Psychology, 37*(2), 87-101.

Turnbull, H.R., & Turnbull, A. P. (1989). *Report of consensus conference on principles of family research.* (Available from the University of Kansas Bureau of Child Research; Beach Center on Families and Disability; 3111 Haworth Hall; Lawrence, Kansas 66045).

The Symposium: Introductory Remarks

Holly Echo-Hawk, M.S., Facilitator

We all have a lot in common. We all care very deeply about the communities that we come from and about American Indian and Alaska Native communities across the country. We all share deep concern about the well-being and future of Indian children and families. We are all very self-sacrificing. We are in this business because of our personal beliefs and our desire to make a difference. Our personal backgrounds, our training, our education, and our professional experiences all contribute to our desire to make a difference.

There's another thing that we share in common, and that is that we are privileged in a very special way. We are privileged to be of American Indian or Alaska Native ancestry, or we are privileged to be invited into those communities and into those families. Let me share a story with you.

When I was 10 years old my family had a Native American Church prayer meeting for me, and I remember that very profoundly even though I was a little girl. Decades later, when my son was about the same age, I had a Native American Church meeting for him at the same place. When we held the prayer meeting for my son, people came from all over—from Navajo, from different tribes in Oklahoma, and of course my family was there as well. The church members pray for a long time before they arrive, and they prayed not just for my son but for all the generations that come forward from him. When you're sitting there and you hear a roar of prayers in all different languages—Navajo, Pawnee, Sioux, and English—it's a very powerful and privileged experience. I wanted to share this with you because I think it's important to remember what we are here for—that is, for the future generations.

I am privileged to be here with you all, because the work you do, the words you write, the research you conduct, the information you seek to gather from Indian people, is very special and should be very protected. You hold a tremendous amount of power, and your valuable tools of written information can either be very, very useful to tribal communities—or very harmful.

I am fortunate to be here because this is a gathering of people who want to critically examine their work so that it is of the most use to tribal communities and to the generations that follow.

The last thing I wanted to mention is one of the creeds that I live by, which is "First do no harm."

So, with that introduction of myself, I thank you all for allowing me to facilitate your conversation for the next two days.

Part II
Papers

A Brief History of and Future Considerations for Research in American Indian and Alaska Native Communities

Jamie D. Davis, Ph.D.
Kelly Keemer

Abstract

The authors explore the relationship between the historical treatment of American Indian and Alaska Native people and research practices in these communities. Forced acculturation, exploitation, and other injustices contributed to feelings of inferiority and mistrust of investigators as well as of the research process. Participatory research methods and tribal research codes of ethics have helped transform the research process for American Indian and Alaska Native communities to one that is beneficial for Native people as well as for researchers. Future research needs in American Indian and Alaska Native communities are discussed.

Historical views about individuals and communities shape the ways that researchers interact with people and their communities. The European settlers thought of Native Americans as savages in need of socialization. Accordingly, as scientists began investigating American Indians, there was little concern for the needs of these people and their communities. "Civilization" brought new diseases and social problems to these communities and, with them, an opportunity for researchers to impose Western scientific values to solve these problems for Native communities. More recently, significant strides have been made in involving American Indians and Alaska Natives as partners in the study of physical, emotional, social, and environmental problems. Such partnerships are beneficial for researchers as well as for American Indian and Alaska Native people and their communities.

Although the focus of this paper is the indigenous peoples of what is now the United States and Canada, the need to develop true collaborations with indigenous people has no boundaries. It is in this spirit that we write this paper—with the hope that it will, in some small way, contribute positively to the health status of indigenous peoples and close the gap of health care disparities in these communities.

Historical Perspectives on Research in American Indian and Alaska Native Communities—Lessons Learned

Paternalism—Conducting Research on *Native Americans*

The mistreatment experienced by American Indians for centuries has resulted in little tolerance for non-Natives who wish to conduct research in Native communities. American Indians and Alaska Natives have come to believe that researchers often do not recognize the rich diversity of each Nation and, instead, may catalog the more than 500 federally recognized tribes as equivocally *Indian*. Acknowledging the diversity of Indian peoples and thus the uniqueness of each tribe is fundamental to gaining the trust and respect of the community. Few researchers understand the influence traditional values and beliefs have on the lifestyles of American Indian and Alaska Natives; for the scientist, such values rarely have significance for research (Davis & Reid, 1999). For American Indian and Alaska Native people, cultural values represent a way of life.

A relationship exists between the historical treatment of American Indian and Alaska Native people and the research methods used

to study these individuals. A search of the Native Health History Database (http://hscapp.unm.edu/nhhd) by the authors of this paper revealed that published research has been conducted on American Indians since the early 19th century. Written accounts of American Indians certainly existed well before this time but were primarily observations made by missionaries and military personnel (e.g., see Oliver, 1764).

At best forced acculturation and at worst annihilation were imposed on the indigenous peoples of North America. The first reservation was established in Connecticut in 1638, officially signaling the beginning of relocation efforts—efforts that would later tear at the very fabric of the collective nature of all American Indian communities (Equity Center Infoline, 1999). Native communities, entire tribes in many instances, were destroyed. Following this period of destruction and initial relocation came the second phase of extensive relocation and forced removal of the early- to mid-1800s. Research written during this historical era reflects the Eurocentric beliefs about American Indians. One such example is the 1857 article authored by Dowler titled *Researches into the Sanitary Condition and Vital Statistics of Barbarians*. American Indians were considered savages incapable of caring for themselves, much less of engaging in scholarly activities such as conducting research. Although the many efforts of the U.S. Government (e.g., forced removal and distribution of disease-infected blankets) were unsuccessful at destroying the Native Americans, new strategies were employed.

In 1879, the Carlisle Indian School was established in Pennsylvania. The motto of Carlisle was "Kill the Indian, save the Man" (Styron, 1997). This *new* method, assimilation, although different from forced removal and genocide, was no less destructive to the individuals and communities exposed to boarding school policy. An 1872 statement by George Grant, a Presbyterian minister who traveled across North America documenting his observations, was prophetic:

> As the Indian has no chance of existence except by conforming to civilized ways, the sooner that the Government or the Christian people awake to the necessity of establishing schools among every tribe the better. Little can be done with the old, and it may be two, three or more generations before the old habits of a people are changed; but, by always taking hold of the young, the work can be done (Styron, 1997).

Research of this era supported this notion that western education was the only hope to reform the *amoral* practices of Native Americans. Elliott authored one such article, "Wild Babies," in 1878.

Federal legislation mandated compulsory schooling for Natives. By 1887 there were 167 schools both on and off the reservations with an enrollment of nearly 15,000. In 1902, of the nearly 200 Indian schools, 25 were federally sponsored off-reservation. The number of boarding schools continued to increase throughout the early 1900s; such schools were located in over 15 states and territories (The Brown Quarterly, 2001; Equity Center Infoline, 1999).

Although sympathizers with the "Indian condition" were increasing in numbers, research practices were paternalistic. Even though many American Indians experienced considerable injustices at the hands of educators and missionaries, the education these individuals received undoubtedly contributed to the eventual evolution of research practices in American Indian and Alaska Native communities.

Interestingly, it was not until 1924 that all American Indians were granted U.S. citizenship (American Indian Lawyer Training Program, Inc., 1988). The paternalistic approach to interactions with and research on Native peoples continued into the 20th century. Research conducted in the 1920s through the 1940s included *Mental Disease Situations in Certain Cultures—A New Field for*

Research (Cooper, 1934), *Medical Observations Made on Zuni Indians* (Flemming, 1923), and *Studies in the Dietaries of Contemporary Primitive Peoples* (Klatsky, 1948).

During the 1950s the U.S. Government again decided it knew what was best for American Indian people. The years between 1953 and 1962 are known as the "termination experiment" (American Indian Lawyer Training Program, Inc., 1988, p. 13). These are the years of the Termination Acts. The federal government believed that over 100 American Indian tribes should be able to assimilate into the larger society without the benefits and services afforded through trust responsibilities (American Indian Lawyer Training Program, Inc., 1988).

During this period it was not uncommon for researchers to collect data without the full knowledge and consent of participants and without respect for local culture and tradition (Hodge, Weinmann, & Roubideaux, 2000; Macaulay, 1994). At one time (and even in contemporary times), it was not uncommon for *helicopter research* (Hodge et al., 2000) to take place in Native communities. The term helicopter research describes the way in which investigators *fly in* to collect the data and *fly out*, having little or no interaction with the community. These researchers leave without obtaining community endorsement or considering the needs of the community, to publish findings that tell only of the health and health care disparities and problems found in the American Indian and Alaska Native communities studied. Often community members are unaware of the purpose of the study; benefits to the community are unknown. Such research practices have led to feelings of exploitation and inferiority when researchers try to gain entry into a Native community. This can result in an unsuccessful research project (Davis & Reid, 1999). Many tribal communities have become protective and, at times, prohibit researchers from their communities.

Joining—Conducting Research with *Native Americans*

Although research practices continued to neglect the needs of American Indian and Alaska Native communities, the evolution of anthropology and social science research, coupled with the changing political climate in the U.S., led to some changes in the way research was conducted in these communities. The Nixon administration passed the Indian Self-Determination and Education Assistance Act (Pub. L. 93-638) in 1975, supporting the autonomy of American Indian and Alaska Native communities (Kunitz, 1996). Although first developed in the early 1960s, the Indian Health Service (IHS) policies, procedures, and responsibilities for research activities were significantly updated in 1977, 1982, and 1987. These new policy documents set forth the guidelines and oversight for research activities, including the Protection of Human Subjects, the IHS Institutional Review Board (IRB), Area Research Committees, and the Director of Research (Indian Health Manual, 2001). In addition, a latent benefit of assimilation and forced education was emerging; American Indians and Alaska Natives were obtaining advanced degrees and beginning to influence the research process. Carolyn Attneave, a Delaware and Cherokee psychologist, is one such example. Her work on the importance of culture for families and communities helped change the way researchers thought about and conducted research (see, e.g., Attneave, 1982).

During the 1970s, researchers began working *with* Native communities—that is, they began to involve Native communities in the research process, but still without true collaboration. Consideration for American Indian and Alaska Native community needs is evident in the research of this era. Several examples of research during this period are representative of this paradigm shift. Patrick and Tyroler's (1972) research, reported in *Papago Indian Modernization: A Community Scale for Health Research,* focused on community needs; Taylor (1975) consulted with tribal members in

developing his *Cherokee Tribal Health Evaluation Report*, and Brelsford (1977) authored *Cgwangkumtenek Sungcarluta*, consulted with Alaska Natives, and incorporated Alaska Native language into his paper.

Consultation is not collaboration. Foulks (1989) candidly discussed the mistakes made and the resulting misalliances in a study of alcohol use among the Inupiat. Although the investigators established a Steering Committee that consisted of local Inupiat leaders and a Technical Advisory Group (mostly made up of non-Native professionals), the investigators were unable to reach consensus about the content of the report in conjunction with the Steering Committee and the Technical Advisory Group. When a press statement was released about the results of the study the headlines read, "Sudden Wealth Sparks Epidemic of Alcoholism: What We Have Here is a Society of Alcoholics" (Foulks, 1989, p. 13). The community was outraged. A non-Native faculty member of the Inupiat University of the Arctic summed up this outrage:

> [T]he North Slope Borough Assembly has been the victim of a sophisticated hoax aimed at destroying the credibility and integrity of the Inupiat people. The research on alcohol abuse and the news coverage was the most demeaning and reprehensible sham. Instead of using Winchester and Remington rifles to destroy a people and a culture, as with the Indians in the 1880s, they bent words, numbers, and statistics to accomplish what was in effect a social and cultural genocide. These con artists hiding behind the guise of professionalism and religiosity, and acting as consultants to the North Slope Borough have dealt a devastating blow to the Inupiat people and their cultural heritage (Foulks, 1989, pp. 14-15).

Such violations of trust by researchers in American Indian and Alaska Native communities negatively affected the willingness of these communities to participate in the research process (Norton & Manson, 1996).

Even the most recent research sometimes overlooks the nuances important for conducting research in American Indian and Alaska Native communities. In an important and generally well developed study of recruiting American Indians and Alaska Natives into clinical trials (Hodge et al., 2000), the term *subjects* is still used to describe research participants. Such language minimizes the value of the individuals who partner with researchers.

Collaborating—Conducting Research in a Participatory *Fashion*

Participatory Research

Research has quantified and described some of the realities of American Indian and Alaska Native people but has contributed little to improve this reality (Dickson & Green, 2001). Despite the problems of the past, American Indians and Alaska Natives realize the need for research and health promotion projects in their communities. *Participatory research* (PR) represents an active step in improving research so that the research benefits the communities studied. Simply stated, PR empowers people to become responsible for addressing the issues that affect their lives.

Participatory research begins with the idea that people can and must benefit from the research conducted in their communities. It is important that both scientists and community members share equally in the research planning, implementation, evaluation, and results dissemination phases as well as in any resulting benefits (Davis & Reid, 1999). The principles of PR clearly define the roles of the partners who are collaborating for the benefit of the community. The ultimate goal of participatory research is to empower communities to assume ownership of the research process and to utilize the results to improve their quality of life (Macaulay et al., 1998). Only research that primarily considers the interest(s) of the community, not just the interest(s) of the larger

society, can bring significant benefits to the community served.

Researchers must approach the community in a respectful manner. A community meeting that explains, in layman's terms, the goals of the project to all interested community members will allow for questions to be answered and misunderstandings to be addressed. "In recent years, many tribes have formed their own Institutional Review Boards (IRB) to obtain some degree of control in the research process and to halt the perceived misuse and misinterpretation of data" (Hodge et al., 2000, p. 43). Tribes evaluate research projects to determine whether hypotheses are of interest or results will provide benefits to the tribe; researchers must gain the approval of the tribal IRB. "Obtaining consent from tribal governments may involve significant time, preparation, and expense, which must be considered in planning grant applications and project deadlines" (Norton & Manson, 1996, p. 858). If research is to be conducted at an IHS facility, approval from the IHS IRB must be obtained.

"It is not necessary for the researcher to know all the cultural distinctions. Rather, it is important that the researcher be aware of cultural differences" (Hodge et al., 2000, p. 43). Researchers are not expected to be experts on the more than 500 American Indian tribes and Alaska Native villages, but should learn as much as possible about the local community and tribe they plan to study. Investigators may become involved in the community through attending tribal meetings and social gatherings. Learning more about the history and culture of the tribe as well as local customs and beliefs about illness will allow the researchers to conduct a more efficient study that will prove successful to both parties involved. Showing genuine concern as well as a willingness to learn and be a part of the community can foster trust.

Once the tribe or community has consented to or approved a research project, guidelines should be established collaboratively between the community and researchers. A Code of Research Ethics was developed in partnership with the Native Mohawk community of Kahnawake in Canada (Macaulay et al., 1998). The document demonstrates new concepts in the sharing of power and decision making for both the researchers and the community. Guidelines for conducting PR entail developing a policy statement, discussing the obligations of all parties involved, developing a data control plan, and developing a plan for disseminating results.

The Kahnawake policy statement ensures that the cultural values, perspectives, and wishes of the community are firmly incorporated into the research plan; they emphasize the need for community empowerment (Macaulay et al, 1998). The following is an excellent example of a policy statement:

> The sovereignty of the Kanien'keha:ka (the people) of Kahnawake to make decisions about research in Kahnawake is recognized and respected. The benefits to the community as a whole and to individual community volunteers should be maximized by the researchers. Researchers should empower the community to support community goals of health and wellness, to promote healthy lifestyles, improve self-esteem and to fulfill its traditional responsibility of caring for the Seventh Generation. (In Mohawk tradition, the Seventh Generation represents those as yet unborn) (p. 107).

The obligations of the researchers include maintaining continuous consultation and collaboration on all aspects of the research, involving the community through active participation rather than passive acceptance, transferring new skills to the community during the research process, and helping to address any health or social issues raised as a result of the research.

The obligation of community-based researchers is to maintain a long-term relationship of trust in their dual role as

caregivers-educators and researchers. The needs of the community should retain priority in any decision. The obligations of the community include meeting regularly with the researchers, promoting the objectives of the project, offering advice for the development and interpretation of the study, controlling the data after the project ends, and providing dissenting opinions, if needed, at the time of publication.

Community control of the data throughout the research process can help ensure appropriate use of the data (Macaulay et al., 1998). The community maintains control over the dissemination of the results in the PR model. The ultimate decision on how the results are to be used, including whether to publish in scientific journals, resides with the community. Results should be presented to the tribal council and community members in a form that is interpretable and meaningful as well as in a manner that may be used by service providers and administrators (Macaulay et al., 1998, Norton & Manson, 1996).

The study of diabetes mellitus and atherosclerosis in a Mohawk community (Montour & Macaulay, 1988) provides insight about successful dissemination of results. The findings of this study pointed to the serious negative consequences of diabetes for the community. The results were presented to various community groups over several sessions as well as broadcast on the local community radio station. Immediately after the results had been distributed, the Health Department began to note an increase in the number of people being screened for diabetes and seeking counseling for dietary changes, weight loss, and exercise. The schools banned junk food and initiated a daily exercise period for all faculty and students. This study, and the way the results were presented, led to a positive change within the Mohawk community.

Participatory Action Research[1]*: Lessons Learned with Aboriginal Grandmothers*

A two-and-a-half year program was designed to examine the unmet health needs of older urban aboriginal women and to study *participatory action research* (PAR) as a research method and intervention for health promotion (Dickson & Green, 2001). The primary goal of the assessment was to strengthen the Grandmothers' sense of self-worth. The Grandmothers' initial response was that research was *something done to them* for the benefit of the outsiders. The project was a success because the researchers partnered with the Grandmothers. A sense of community was fostered between the Grandmothers and researchers. The Grandmothers' roles in the research process were highly valued; they designed interview guides, consent forms, work plans and contracts, and provided secondary analysis and verification for interpretation of the data. The final report consisted largely of the Grandmothers' words and was approved and released only after extensive review. "Faith in the long-term process is essential for all participants of PAR because social and political change does not occur readily" (Dickson & Green, 2001, p. 481). The project concluded that, given the opportunity, support, and tools, Native people have the capacity to conduct research that is meaningful to them and contributes to their personal and social change.

Participatory research balances the needs and wants of the community with those of the researchers; without this balance trust may be broken and significant problems may arise. The *give and take* approach is one that allows community members and researchers to

[1]PAR goes beyond PR by insisting that researchers offer tribes the support and tools to implement (i.e., take action) the research findings that will enable tribes to develop effective and culturally appropriate intervention and prevention programs. A body of literature discussing the differences of PAR and PR exists and a review is beyond the scope of this paper (see Marshall et al., this monograph).

remain equal partners; if researchers make use of participants' ideas, time, and/or bodily fluids, they must give back skills, employment, and/or training (Davis & Reid, 1999). Communities will benefit from research by simply addressing relevant concerns of the tribes and other Native communities. "Researchers who demonstrate a long-term commitment to the communities that they propose to study, and who are willing to enter into the partnerships implied by such commitments, will receive greater cooperation and support of their work" (Norton & Manson, 1996, p. 859).

Best Practices

A number of research codes of ethics exist, specifically developed by American Indian and Alaska Native communities. Here we present, in chronological order, a brief description of three formalized and one informal ethics codes. Also included in this section is a brief presentation of "cultural case formulation" and its relevance for research.

Macaulay et al. (1996) developed a formalized code of research ethics to guide researchers as well as community members throughout the entire research process. The development of this ethics code involved academic researchers, community-based researchers, and the community in defining the various roles, from the initial research question and design of the project to the dissemination of research results. Specifically,

> The three partners will work cooperatively and collaboratively in the design, implementation, analysis, interpretation, conclusion, reporting, and publication of the experiences of the project. Each partner provides ideas and resources that come from the experience, knowledge, and capability of its members. Together, through respect for each other, consultation, and collaboration, they significantly strengthen the project and its outcomes. All three partners of the project share an understanding that community-based research is a powerful tool for learning about health and wellness, while contributing to the health of the community in which it is being conducted (p. 39).

The Model Tribal Research Code was developed by the American Indian Law Center, Inc. (1999). This 28-page document represents an extensive evaluation of the need for such a code for American Indian tribes and Alaska Native villages and presents information about the appropriate as well as the inappropriate uses of such a code. Specific aspects of developing a research code of ethics, including a discussion of policy statements, scope, process, and enforcement, are presented and discussed thoroughly. In addition, a Model Tribal Research Code template is included in the document as is a checklist to aid tribal health boards and others to evaluate effectively the appropriateness and usefulness of a research proposal.

Though not a formal ethics code, the Strong Heart Study (Stoddart, Jarvis, Blake, Fabsitz, Howard, Lee, & Welty, 2000), a large-scale multisite study of cardiovascular health, represents an excellent example of appropriate recruitment of American Indians into medical research. Collaboration with the IHS began early in the pre-award stage of the project and participating communities were involved in the proposal evaluation process and the methodology development process. Participating tribal members developed posters and logos used to inform and recruit community members. Brochures were developed to explain the purpose and rationale of the study, the procedures that would be utilized, and a community-identified point-of-contact who could answer questions and schedule appointments for participation in the study. Community-based recruiters contacted potential participants. Mass mailings and local radio broadcasts were used to promote participation in the study. Recruitment strategies included benefit powwows and health fair participation. The success of this study is attributed to the

multimethod recruitment strategy employed (i.e., meeting the various needs of potential participants) as well as to the respect for community needs, cultural differences, and the flexibility used to meet the needs of the researchers and the research participants.

The National Science Foundation Arctic Program developed Principles for the Conduct of Research in the Arctic (http://www.nsf.gov/od/opp/arctic/conduct.htm). These guidelines were developed to "promote mutual respect and communication between scientists and northern residents" (p. 1). The 13 principles emphasize the need to assess scientific investigations in terms of the potential impact on and interests of Native people and their communities. The recommendations outline the need to obtain full and informed consent explained in terms understandable to the community; to consult with the communities throughout the research process; to communicate results in a manner responsive to community needs; to provide appropriate credit for community contributions; and to respect anonymity, local cultural traditions, cultural property, and sacred sites.

Historically, the Diagnostic and Statistical Manual of Mental Disorders (DSM) has paid little attention to the role of culture for psychiatric diagnosis. The Fourth Edition of the DSM (American Psychiatric Association, 1994) breaks from this tradition and acknowledges the importance of culture for "the expression, course, treatment, and existence of psychiatric disorders" (Christensen, 2001, p. 53). Christensen discusses the relationship between cultural competence and psychiatric diagnosis and presents an example of cultural case formulation for an American Indian client. Cultural identity; cultural explanations of illness; the relationship among the psychosocial environment, culture, and levels of functioning; and cultural and social status differences between the individual and the clinician are components necessary to understanding the role of culture for the individual. Although not specifically designed for research purposes, these principles are relevant for researchers studying psychiatric disorders as well as researchers conducting nonclinical investigations.

The Future of Research in American Indian and Alaska Native Communities

Research practices have changed dramatically over the past 150 years. American Indian and Alaska Native communities demand that research benefit their people *and* that the research be conducted in a collaborative and participatory manner. Continuing to develop research that addresses the health needs of American Indian and Alaska Native people is of vital importance. The goal of this section is to foster thoughts about the future direction of research in these communities and for these people.

Research that addresses the use of direct service referrals by providers, employers, schools, union, family members, and self-referrals is needed. Such research will help communities understand how to make better use of available resources. Augmenting knowledge about service utilization rates can increase awareness about who is not being reached and how better to include these individuals. This type of research has particular relevance for elders and individuals with disabilities. Stigma also influences utilization rates. Understanding what contributes to stigma in a particular community, and what can done to minimize the effects of stigma, can help the community develop more effective outreach programs.

Encouraging employment of tribal members in tribal programs is necessary; however, important issues can occur when family members, friends, or neighbors provide services or work in these programs. Individuals may be reluctant to disclose information openly to community members if there are concerns about indiscreet use of personal information. For example, concerns about confidentiality may develop when

family members work for health programs. Research may be able to help us gain a better understanding about such issues.

Research often focuses on the *problems* or concerns faced by a community or group of individuals. Additional research focused on strengths is needed to help clinicians better utilize the inherent strengths of individuals and promote wellness.

Considering the history of problems relative to conducting research in American Indian and Alaska Native communities, considerable disparities exist in what we know about these communities as compared with what we know from research about the general population. Children, women, aftercare, violence, health care, traditional medicine—nearly every facet of life for Native people is fertile ground for investigation to benefit the people and the Nations.

Conclusion

Research is essential for understanding the health and well being of American Indian people. The usefulness of research is diminished when the community's vitality is overlooked. Communities are made up of people—individuals who live, breathe, and love, individuals who feel pain as well as joy. Several tribal research codes of ethics are available to aid investigators in designing appropriate research (e.g., American Indian Law Center, Inc., 1999; Macaulay et al., 1998). Existing models, such as the participatory action research method (Dickson & Green, 2001), provide practical examples of effective research practices in American Indian and Alaska Native communities. Both researchers and community members can benefit by establishing effective research partnerships.

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Research in Indian Country: Challenges and Changes

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Abstract

Selected settings, circumstances, problems, and barriers to research in Indian Country are described and ways to mitigate or overcome these problems and barriers are discussed. The reemergence of Indian self-determination and self-governance, federal requirements for review of research by institutional review boards (IRBs), and the Office of Management and Budget (OMB) have greatly affected the ways research is conducted in Indian Country. Tribes are gaining increasing influence over setting research agendas and funding priorities, and have, at a minimum, the power to reject unwanted research on their lands. Increasingly, researchers are required to identify and justify to concerned tribes the costs, benefits, and risks associated with participation in a study.

This paper describes selected settings, circumstances, problems, and barriers to research in Indian Country[1], and suggests ways to mitigate or overcome these problems and barriers. Examples of issues, problems, and approaches taken from actual research projects are presented in four text boxes distributed throughout this paper.

Background

Stakeholders of Research in Indian Country

The distinction among sponsors, consumers, and stakeholders of research in Indian Country is central to the theme of this paper. The primary *sponsor* of research in Indian Country is the federal government, with research generally conducted for or by federal agencies. These agencies may conduct the research directly using their own staffs. More often, however, agencies fund the research, which is conducted, under contract, by other entities and organizations. The *consumers* of research conducted in Indian Country include the organizations conducting the research, the sponsoring agencies, Congress, universities, and other research institutions. In recent years, consistent with the principles of Indian self-determination and self-governance, sponsors of research in Indian Country have started to relate to Indian tribes and Alaska Native villages (and related organizations) as consumers of the research findings. *Stakeholders* of research in Indian Country include sponsors, consumers, tribes, Alaska Native villages, their members, tribal consortia, Indian organizations, and Indian people who are not members of a tribe.

Because there are more than 550 Indian tribes and Alaska Native villages within the United States, national and regional associations, organizations, and consortia represent important stakeholders of research in Indian Country, especially research that includes or affects more than one tribe. These Indian organizations are often organized around a particular area of interest. Examples include the National Congress of American Indians (NCAI), the National Indian Health Board (NIHB), the National Indian Education Association (NIEA), and the American Indian

[1]Throughout this paper, *Indian Country* refers to any lands owned by American Indian tribes, Alaska Native villages, and consortia of tribes or Native villages, and to locations where large numbers of American Indians or Alaska Natives reside. Unless otherwise indicated, *Indian* refers to members of American Indian tribes, Alaska Native villages, and their descendants.

Higher Education Consortium (AIHEC). In addition, most tribes and Alaska Native villages are members of consortia or regional organizations such as Bristol Bay Native Corporation and the Tanana Chiefs Conference in Alaska, the United South and Eastern Tribes (USET), the All Indian Pueblo Council (AIPC), and the Southern California Tribal Chairman's Association (SCTCA).

Federal Agencies Sponsoring Research in Indian Country

Occasionally Congress mandates studies and other forms of research in Indian Country; however, the bulk of the research is procured by or conducted by federal agencies. Most of this research is guided by each agency's mission and goals; in addition, some research is conducted to meet the requirements of the Government Performance and Results Act (GPRA) of 1993 that requires strategic planning and annual program performance reporting for every federal agency. In passing GPRA, Congress sought improved accountability for program performance and better planning of federal programs. GPRA has resulted in increased evaluation and other research to demonstrate program results.

Federal agencies that have conducted or sponsored the greatest amount of research in Indian Country include the Department of Health and Human Services (DHHS), the Bureau of Indian Affairs (BIA), the Department of Justice (DOJ), and the Department of Education (ED). Among these agencies, DHHS sponsors the greatest amount of research. Within DHHS, research is funded by the Indian Health Service (IHS), the National Institutes of Health (NIH), the Substance Abuse and Mental Health Services Administration (SAMHSA—which includes the Centers for Substance Abuse Treatment [CSAT], the Center for Substance Abuse Prevention [CSAP], and the Center for Mental Health Services [CMHS]), the Centers for Disease Control (CDC), the Administration for Native Americans (ANA), and the Administration for Children and Families (ACF).

In the last 10 years, DOJ has become increasingly active in promoting research in Indian Country. Within DOJ, agencies active in conducting or funding research include the Office of Justice Programs (OJP), which includes the National Institute of Justice (NIJ), the Drug Courts Program Office, and the Office of Juvenile Justice and Delinquency Prevention. Educational research in Indian Country is funded by both the BIA and ED. Other federal agencies that sponsor research in Indian Country include the Departments of Labor (DOL), Housing and Urban Development (HUD), Commerce (DOC), and Transportation (DOT).

Increasingly, but slowly, federal sponsors of research have begun to consult with tribes and tribal organizations in setting the agendas and guidelines for research to be conducted in Indian Country. Congress and federal agencies are soliciting input from tribes and tribal organizations with respect to research goals and research budgets. Some examples of agencies would be:

National Indian Health Board
http://www.nihb.org/inside_budget.htm

National Congress of American Indians
http://www.ncai.org/main/pages/legislative_updates/index.asp

United South and Eastern Tribes, Inc.
http://usetinc.org/resolutions.html

National Indian Education Association
http://www.niea.org/2001niearesos.pdf

Tribes and tribal organizations track proposed legislation and provide information to congressional representatives and their staffs and to congressional committees. Federal agencies often require researchers to establish project advisory committees that include tribal officials and experts on related research in Indian Country.

Nature of Research Conducted in Indian Country

The full range of research activities occurs in Indian Country, including randomized experiments, clinical trials, field experiments, quasi-experimental research, retrospective and prospective studies, cross-sectional and longitudinal studies, survey research, feasibility studies, evaluation research (including outcome, impact, and process evaluations), ethnographic research, participant observation, and case studies. The types of research conducted in Indian Country are not distributed evenly across sponsoring agencies. Most of the randomized experiments and clinical trials are conducted under the auspices of the NIH. For methodological (e.g., sampling) and logistical reasons, most research takes the form of evaluations, particularly process evaluations, feasibility studies, and case studies.

Sampling issues are especially problematic for research in Indian Country because of an implicit political dimension—the heart of sampling involves the selection of a subset of a defined universe or population. As a rule, it is not practical to define the universe population of interest as "members of all Indian tribes" or "all Indians" because there are over 550 federally recognized tribes, and there is great variation across tribes—variation in language, culture, location, economy, and a host of other factors. Thus, some researchers have discovered something that eludes many non-Indian people—American Indians are not a homogeneous group; rather, most are members of unique tribes. Compounding the sampling problem is the large American Indian diaspora—more Indians reside in cities and other off-reservation locations than on or near reservations and other tribal lands (Hillabrant, Romano, & Stang, 1992). Because of the great diversity across tribes in many domains, research findings obtained at one tribe, or on a group of tribes, may not be representative of other tribes. To plan and draw a representative (i.e., random) sample of American Indians and/or Alaska Natives residing on or near tribal lands would be a daunting task, beyond the means and resources of most research projects. Identifying a sample frame and drawing a representative sample from a single tribe or a group of tribes often presents problems that challenge the resources available to most research projects. Data commonly used to identify primary sampling units are often incomplete or unavailable. For example, many individuals may reside in dwellings without a published address or even a named street, lack Social Security numbers or telephones, may have multiple residences, and may be away from their primary residence for long periods of time fishing, hunting, trapping, and gathering/harvesting. Many of these challenges can be attenuated and managed through close collaboration with tribal officials and residents of the communities participating in the research.

Of course, it is possible to draw random, stratified random, probability proportionate to size, and multistage samples of well-defined groups in Indian Country. For example, a prospective study of substance abuse treatment outcomes included a first stage selection of 22 treatment facilities probability proportionate to size (number of clients served the prior year) within strata (IHS Areas), and quota samples of all clients accepted for treatment at randomly determined start dates (Hillabrant, Earp, & Rhoades, 2001). In a retrospective study of youth residential substance abuse treatment facilities, random samples of client records were selected for review at each of nine facilities (Hillabrant, Earp, & Brutus, 1997). An assessment of the expected impact of a change in the rule governing eligibility for services from the IHS included a random sample of the IHS user population—all IHS beneficiaries using an IHS or tribal facility in the last 3 years (Hillabrant, Earp, & Brutus, 1996). In this study, the sample frame was defined by automated patient registration and utilization data.

Emerging Tribal Influence on Research in Indian Country

Over the last 25 years, tribes, Native villages, and consortia have taken an increasingly active role in controlling research conducted in Indian Country. This active stance reflects the increasing autonomy exercised by tribes in taking control over programs such as education, the provision of health care services, employment, training programs, and welfare programs formerly operated by federal agencies. With the enactment of the Indian Self-Determination and Education Assistance Act (ISDEAA) of 1975 (Pub. L. 93-638), tribes began to exercise ever-increasing levels of control over programs, policies, and research affecting their members.

The increase in tribal control of research has been abetted by federal regulations requiring protection of people participating in research (21CFR Part 56). These regulations require that all research involving human participants be reviewed and approved by an institutional review board (IRB). Now, some tribes have constituted their own IRBs, which review all research conducted on or near the reservation in which tribal members are participants in the research. Regardless of whether or not a tribe has instituted an IRB, tribal approval is required for any research conducted on tribal lands.

The concern about protection of people participating in research, in turn, reflects revelation of unethical research in which participants were not informed about the risks involved or were deprived of treatment and care that could have saved their lives or ameliorated their conditions. Among the most publicized unethical research are 1) a study sponsored by the U.S. Public Health Service in which 400 African American men in Macon County, Georgia, were deprived of medication to cure syphilis and not told of their illness, putting others at risk of contracting the disease (Tuskegee Study); 2) a study conducted by the U.S. Army in which soldiers were given the drug LSD; and 3) studies where prison inmates and terminally ill patients received injections of cancer cells to study the response of their immune systems (Lemonick & Goldstein, 2002).

Overcoming History of Exclusion from Control of Research

In the 1800's, often after successful military campaigns and other conflicts with American Indians, the United States treated Indian people as wards of the federal government (*Cherokee Nation v. Georgia*, 1831; American Indian Policy Review Commission, 1997). In this trustee capacity, federal agencies, often acting through the BIA and, later, the IHS (with respect to health care), determined what research would be conducted, which tribes would participate in the research, and which tribal members would serve as research participants. While the legacy of this trustee relationship still reverberates today, tribes have increasingly expanded their sovereign control over programs affecting their members since the passage of ISDEAA in 1975. Because of a long history of exploitation and both benign and hostile neglect by the United States, many tribes and tribal organizations want to be involved in all aspects of research in Indian Country, including planning, design, data collection, reporting of, and dissemination of research findings. Tribes and tribal organizations are requiring that researchers 1) hire tribal members to assist in data collection and other research activities; 2) demonstrate how the research findings will benefit the tribe and tribal members; 3) guarantee that the research protocol does no harm to the tribe, tribal members, and the environment; 4) guarantee confidentiality or anonymity of research participants, tribal communities, and the tribe; and 5) publish results only after review and approval of the manuscript by tribal representatives (see e.g., American Indian Policy Review Commission, 1997). These requirements and limitations increasingly exercised by tribes can both benefit and impede research in Indian Country.

1. ***Hire tribal members.*** Requiring researchers to hire tribal members to assist in research activities can have several benefits. Such hiring increases employment and contributes to the tribal economy. Tribal members assisting with the research acquire skills and knowledge. Having tribal members participate on the research team is associated with other benefits, including:

   a. The research team is less likely to exploit research participants, expose them to unnecessary risk, or demean them.
   b. Researchers are less likely to employ or express invalid stereotypes, or to express, explicitly or implicitly, prejudicial perceptions, opinions, or expectations.
   c. Often, the quality of the data collected is improved because of enhanced communication and better rapport between the researchers and the study participants.

On the other hand, employing tribal members on the study team may be associated with a variety of costs. Hiring, training, and using tribal members on a research team can increase both the time required to complete the project and project costs. Using tribal members to collect data can create special problems for study participant confidentiality, and change the demand characteristics of the research (Orne, 1962). Study participants may conceal taboo or socially undesirable expectations, beliefs, or behaviors from other tribal members; such expectations, beliefs, or behaviors might be less concealed from outside investigators whom the research participants are unlikely to encounter in the future.

2. ***Demonstrate how the research findings will benefit the tribe and tribal members.*** It is customary for researchers to describe the anticipated benefits (and costs) of the research, especially in preparing grant proposals and in submissions to IRBs and OMB. Prior to the emergence of tribal control of research, discussions of the anticipated benefits of research in Indian Country tended to be abstract, making reference to Indians in general rather than to the participating tribe or tribes. Requiring researchers to relate costs and benefits to the participating tribe(s) tends to clarify thinking and make assumptions and expectations explicit—results often beneficial to the proposed research, the researcher, the participating tribe, and other stakeholders.

On the other hand, research in Indian Country, like research everywhere, is conducted in a social and political context. The perceived benefits and costs associated with a particular study may vary across stakeholders. For example, managers of tribal programs may perceive costs and benefits of a study differently from members of the tribal judiciary or legislature. Proponents of traditional values and approaches may differ from advocates of change. While involvement of tribal stakeholders with conflicting values, agendas, or perspectives can improve the robustness and acceptance of a study, such involvement can also mire the research in conflict, leading to disorganization or even abandonment of the research. Depending on their interests, stakeholders may embrace or repudiate research findings (see Vignette 1).

3. ***Guarantee that the research activity does no harm to the tribe, tribal members, and the environment.*** The level of risk to study participants, the tribe, and the environment and the potential to do harm depend on the nature of the research, with medical clinical research often bearing the greatest risk of harm to participants. However, risk is not limited to medical research, and all research has costs, even if only opportunity costs—time and resources spent on the research activity could be spent on alternative activities. Opportunity costs are especially important in situations where there are significant unmet needs, as is the case in much of Indian Country. Critics of research, including members of tribal IRBs, have suggested that most research funds would be better spent on service delivery. Of course, such judgments should consider the relative costs and benefits of a research project. It is the responsibility of the research sponsor(s) and those conducting the research to present

Vignette 1. Repudiation of unpopular results: Evaluation of the IHS Fiscal Intermediary (FI)

The IHS commissioned an independent evaluation of the performance of the FI in order to determine the degree to which the FI was achieving the goals and objectives specified in its contract. These responsibilities included 1) receiving bills and claims submitted by hospitals, clinics, and other providers outside of the IHS; 2) reviewing the claims to ensure conformance with treatment referrals and authorizations; 3) paying the valid claims and bills; and 4) producing reports of the services provided and amounts paid.

The evaluation was commissioned in the context of strong and ongoing criticism of the FI by staff in IHS and tribal clinics and by tribal officials. The major complaint about the FI was that it failed to pay bona fide claims within the 45-day time frame mandated by its contract with the IHS. Tribal officials were especially frustrated because providers submitted unpaid bills and claims to collection agencies. In turn, collection agencies hounded tribal members for payment of the claims unpaid by the FI.

Site visits to the FI and to IHS and tribal clinics conducted as part of the evaluation produced convincing evidence that the primary causes for the delayed payments were incomplete referrals and treatment authorizations submitted by clinic staffs. As a rule, when the FI received complete and valid information from clinics, it paid the claims in a timely fashion. The evaluation recommended a number of ways that the referrals and authorizations submitted by the clinics could be improved. The evaluation results were accepted by many stakeholders; however, some, hoping that the study results could be used to terminate the FI contract, repudiated the findings and ardently tried to suppress them (Hillabrant, Brown, Weller, & Earp, 1988).

the costs and benefits clearly to the tribe, the IRBs, OMB, and the study participants. It is the responsibility of the tribe, IRBs, and OMB to determine if the benefits outweigh the risks, that the risks do not exceed acceptable limits, and that participants are not exposed to unnecessary risks (see Vignette 2).

There are subtle aspects to the "do no harm" dictum for research in Indian Country. Many consumers of research in Indian Country may be ignorant of 1) the history of exploitation and discrimination faced by Indian tribes, communities, and individuals; 2) the circumstances of many tribes (e.g., remote location, weather extremes, lack of infrastructure); and 3) the legal and constitutional status of tribes. Without knowledge of these circumstances, such consumers are unlikely to appreciate the significance of research

Vignette 2. Risks involved in a screening feasibility study

Three tribes agreed to participate in a study to demonstrate the feasibility of a self-administered, multimedia, computer-assisted screening system to identify adolescents who 1) are victims of physical or sex abuse, 2) suffer from posttraumatic stress syndrome (PTSD), and 3) abuse alcohol and other drugs. The system was to be set up at tribal clinics providing primary care to tribal members; adolescents coming to the clinic for care would be recruited to participate in the feasibility study. All screening research includes the risk of two errors: 1) a *false positive* error occurs when the screening system indicates that the adolescent has been abused, traumatized, or involved in substance abuse when, in fact, no abuse, trauma, or substance abuse has occurred, and 2) a *false negative* error occurs when the screening system fails to detect abuse, trauma, or substance abuse when one or more, in fact, occurred. In addition, other risks associated with the proposed screening included 1) mental health/emotional crisis or problems associated with "hits" (correct detection by the screening system), and 2) adverse consequences should the health care delivery, child protection, or other systems fail to provide services needed by adolescents successfully identified by the screening.

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findings. While such factors are too numerous to list, several favorites of the author include:

- The unique circumstances of Alaska. Many if not most of the people who have never visited Alaska do not understand that it is farther from Anchorage to half-way through the Aleutian Islands than from Washington, DC to San Francisco, CA. Most Alaska Native villages have a single, unpaved road with an airstrip at one end. While there may be 20 trucks and cars in the village, they can leave the road only in winter when the tundra, lakes, and rivers freeze hard.
- Many residences in Indian Country lack electricity, telephones, and running water.
- For over 100 years, to the present day, the United States has been unable to account for money and resources held in trust for tribes and individual Indians.
- Tribes are explicitly mentioned in Article I, Section 8 of the U.S. Constitution (restricts to Congress the power to regulate commerce with the tribes), and citizenship was not conferred on American Indians until 1924, with the passage of the Indian Citizenship Act of 1924.
- Starting in the late 1800s, some Indian children were forced to leave their families to attend BIA boarding schools, where non-Indians prescribed the language they spoke, the religion they practiced, and the material they studied. Growing up apart from their families, frequently subjected to what is now (and often then) seen as physical and emotional abuse, had multiple, cross-generational negative effects on these children, their families, and tribes. While some of these boarding schools still exist, forced separation of children from their families ended, for the most part, by the 1950s.

Because many consumers of research in Indian Country are ignorant of these and other important data, researchers often need to provide background information so that the research results can be understood in context.

4. *Guarantee confidentiality or anonymity of research participants, tribal communities, and the tribe.* Often, tribes do not object to the identification of the tribe or of tribal communities in research reports. Other times, especially when research is conducted on sensitive topics, a tribe may insist that the research report not identify the tribe or communities participating in the research. Protecting the privacy of research participants and keeping their identity anonymous can pose a special challenge for small tribes and communities. If the program being evaluated is small, it can be almost impossible to maintain the anonymity of key informants who provide relevant information (see Vignette 3). Breaches of confidentiality and identification of tribal communities by researchers, despite their agreement not to do so, have been the source of frustration and reactions against research by several tribes (William Freeman, personal communication, June 30, 1999).

5. *Publish results only after review and approval of the manuscript by tribal representatives.* This requirement is often imposed by prudent researchers as well as by tribes. By obtaining review and feedback from the appropriate tribal representatives (generally persons who are knowledgeable about the research topics), researchers can often identify errors or omissions which otherwise might go uncorrected. Thus, such review can improve the quality of research conducted in Indian Country.

Over the last five years, federal sponsors of research have begun to disseminate research findings to all federally recognized tribes, tribal consortia, and Indian organizations. Both the BIA and IHS maintain a "tribal leaders" database available to the public and used as a mailing list for disseminating research reports (see, for example, http://www.ihs.gov/AdminMngrResources_index.asp). Increasingly, research reports are being published on the World Wide Web, available to tribes and the public at large, such as the report from Hillabrant, Rhoades, Pindus, and Trutko, available at the U.S. Department of Health and

Vignette 3. Ethical problem: Substance abuse treatment center director "using"

As part of a national evaluation of substance abuse treatment outcomes, researchers visited 22 treatment programs in Indian Country. At one of the programs, a small facility with a few staff, several staff members told the research team that the program director had relapsed and was "drinking every day, but without becoming grossly inebriated." The staff said that while they did not directly observe the program director drinking, they noted changes in her behavior and claimed to smell alcohol on her breath.

When asked why they did not report this problem to the appropriate tribal authorities, the staff said that there was no one at the treatment facility who supervised the director, and each feared the loss of his or her job if they were to report the problem. Some staff wanted the researchers to pass on the information to tribal officials, but other staff, fearing reprisals, asked the researchers not to pass on the allegations to others. It seemed likely to the researchers that reporting the alleged drinking to tribal officials could not be done without compromising the confidentiality of some of the participants (project staff).

The researchers were unable to independently confirm or disconfirm the alleged drinking by the program director. Some staff said that the program director was able to "remain clean" during the two-day site visit. Alternatives considered by the researchers included ignoring the allegations made by the staff, confronting the program director with the allegations, or passing on the allegations to the office of the tribal chairman.

The members of the research team decided that they would not pass on to tribal officials the allegations made by the staff; rather, they would contact the agency sponsoring the study for guidance. Subsequently, the researchers contacted tribal officials and discovered that the treatment program director had already resigned (Hillabrant, Earp, & Rhoades, 2001).

Human Services website (http://aspe.hhs.gov/hsp/wtw-grants-eval98/tribal02/).

Participatory, Self-, and Empowerment Evaluation

Program evaluation is supposed to be an integral component of program administration and improvement. When the program goals and objectives are formulated or reformulated, the evaluation is to be designed to assess progress toward the goals and objectives, and the evaluation results are to be used to inform and guide reformulation of program goals, objectives, policies, and procedures. Too often, it seems, the evaluation plans are lost or ignored, the evaluation is perceived by program managers and staff as a distraction from their work, and the evaluation results do not have the desired impact on the program.

In reaction to the underutilization or improper utilization of program evaluation, there has been a growing interest in conducting evaluation research in ways that foster improvement and self-determination of organizations, communities, and tribes; this approach has been termed participatory or empowerment evaluation (Fetterman, 2000). Empowerment evaluation seeks to help people help themselves and improve their programs through self-evaluation, reflection, and capacity building. Program participants conduct their own evaluations with the aid of an outside evaluator who often serves as a coach or facilitator. Because of their unique political, cultural, and historical circumstances, Indian tribes may find the empowerment evaluation approach especially useful.

Approval Processes

Obtaining the required approvals for research, especially in the areas of health and education, can be a complex, lengthy, and expensive proposition. Often, there are three levels of review: IRBs, OMB, and tribal; each is discussed below.

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IRBs

Institutional review boards (IRBs) are authorized and required by federal regulations (Title 45, Part 46 of the Code of Federal Regulations [CFR]as well as 21 CFR Part 50, protection of human subjects; 21 CFR Part 56, institutional review boards). These regulations pertain to research sponsored by the Departments of Agriculture, Energy, Commerce, Housing and Urban Development, Justice, Defense, Education, Veterans Affairs, Health and Human Services, and Transportation, as well as to research sponsored by other federal agencies such as the National Aeronautics and Space Administration, Consumer Product Safety Commission, Agency for International Development, and the Environmental Protection Agency. The primary objective of IRBs is the protection of human research participants. This protection is all-encompassing, including physical and mental health. Interested readers are referred to the Office of Human Subjects Research in the DHHS National Institutes of Research (http://www.dvincitbt.com/ohsrsite).

Fundamental to the protection of research participants is the concept of "informed consent." Informed consent means that the study participant understands all the risks and rewards associated with participation in the research. This understanding is to be conveyed to the research participants by the research staff in language that the participant can fully understand. The research participant must indicate his or her understanding of the risks and rewards associated with the research by signing an informed consent form, and the researchers are required to maintain the original forms while the research is being conducted.

In Indian Country, there may be multiple levels of IRB review, including national (agency-wide), area or region, and tribal. While it is possible to submit applications simultaneously to national and area or regional IRBs, it is not uncommon for one group or the other to require the prior approval of the other before completing their review. Since the IRB may meet only once each quarter, obtaining the necessary IRB approval may take one year or more, especially when one of the IRBs requires changes in study protocols, procedures, or data collection instruments. Some IRBs require the principal investigator to make a presentation to the board and to answer questions. Prudent researchers include the costs of such presentations in their budgets and project timelines.

Obtaining informed consent for research in Indian Country involves special challenges. The researcher must be sensitive to the ways that culture affects the participant's understanding and interpretation of the study. Some cultural components may seem relatively obvious, such as the need for presentation of the information in the participant's primary language; however, the difficulties in translation are often revealed by heated discussions among translators as to what expression or metaphor should be used to communicate key concepts or aspects of the research. Other cultural components that affect obtaining informed consent and other aspects of research in Indian Country might include:

- Norms about the expression of disagreement or conflict;
- Kinship systems, the perception of how individuals are related, and norms governing interaction among related individuals;
- Childrearing practices and associated norms and expectations; and
- Models of health and disease and associated norms, expectations, attributions, and perceptions.

Cultural factors that are unknown to the researchers can wreak havoc with research—"it's what you don't know that can really hurt you." One approach to identifying cultural factors likely to affect a study is the use of an advisory committee that includes key informants from the community or communities participating in the research, as advocated by other authors in this monograph. Even with such an advisory committee, unexpected cultural factors can damage research. In an IHS-sponsored national

evaluation of substance abuse treatment outcomes for American Indian and Alaska Native women, no data were obtained from one tribal treatment program because most women served by the program refused to participate in the study. Many of these women were angry because 1) they had been forced to enter into treatment by a judicial proceeding, and 2) men were not required (or allowed) to participate in the study. While these circumstances were not unique to the tribe in question, they interacted with the unique aspects of the tribe's culture pertaining to gender roles; the other 21 tribal programs in the study successfully recruited into the study women in similar circumstances (Hillabrant, Earp, & Rhoades, 2001).

Another aspect of research participant protection is the maintenance of confidentiality of participant data. Researchers must demonstrate to the IRB that no one, except the researchers, will be able to obtain or infer information about individual participants collected during the research. Researchers working in the area of substance abuse can face special challenges to maintaining participant confidentiality. Because substance abuse can include the use of illegal drugs (e.g., marijuana, cocaine, heroin, or the use of prescription drugs without a legitimate prescription), law enforcement officials may request study data and, in particular, the names of research participants who use illegal drugs. Such requests can come in the form of a subpoena issued by a court.

A *Certificate of Confidentiality*, issued by the National Institute on Alcohol Abuse and Alcoholism (NIAAA), authorizes researchers to withhold the names and other identifying characteristics of people who participate as subjects in the research project specified in the certificate. This authorization applies to all persons who, in the performance of their duties in connection with the research project, have access to information that would identify the subjects of that research. Persons so authorized may not, at any time, be compelled to provide the names or other identifying characteristics of the research participants encompassed by the certificate in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings. The statutory authority for the certificate of confidentiality is section 301(d) of the Public Health Service Act (part USC 241 [d]). The applicable regulations are set forth at 42 CFR Part 2a.

OMB Review

The Paperwork Reduction Act of 1995 requires that the Office of Management and Budget (OMB) review and approve all federally sponsored research, other than grants, that includes more than nine individuals. The materials are submitted to the OMB by the funding federal agency; however, contractors and researchers often draft the "OMB submission package" for the client agency. The OMB package includes:

- Justification of the research, including proposed use of the study findings;
- Explanation of information technology used to promote efficiency and reduce the burden of the research participants;
- Explanation of how participant confidentiality will be assured;
- Estimates of burden on research participants and cost of the research;
- Project schedule and publication plans;
- Statistical methods to be used (generally includes sample design, research design, and planned analyses);
- Notices describing the study to be published in the *Federal Register*.

The process of preparing the OMB submission package, responding to questions raised by the OMB, and obtaining the required approval or clearance generally requires 6-12 months. In the past, some agencies have taken the stance that research conducted in Indian Country is exempt from OMB review because of tribal sovereignty. The position taken is that the research is being conducted on behalf of the tribes, and the tribes are not subject to the Paperwork Reduction Act. Such research has

proceeded without obtaining an OMB clearance number and, presumably, without OMB's knowledge.

Tribal Approval

Whether or not a tribe operates an IRB, research on tribal lands requires tribal approval. If the tribe has delegated responsibility for review and approval of research proposals to an agency or office, the review process is greatly simplified. If no such delegation exists, the tribal council, business committee, or other group reviews the research proposal; such review can be a lengthy process. The approval process can be expedited, and the quality of the research improved, if the researchers identify and persuade stakeholders at the tribe of the merits of the study.

An advocate for the research who works for or with each tribe can make the difference between a long review process ending in disapproval, and an expedited, successful review. For example, one tribe approved its participation in the national welfare-to-work (WtW) evaluation within four weeks and approved participation in the women's substance abuse treatment outcome study only after two years of deliberations (Hillabrant, Rhoades, Pindus, & Trutko, 2001; Hillabrant, Earp, & Rhoades, 2001). While the two studies varied across many dimensions, two critical factors seemed to account for the difference in speed of approvals: 1) approval of the tribal IRB was required in the treatment outcome but not in the WtW evaluation, and 2) the WtW evaluation had the strong support of key stakeholders (heads of tribal departments) whereas the treatment outcome study lacked a strong advocate at the tribe. Interestingly, the treatment outcome study was supported by some stakeholders; the substance abuse treatment programs supported the study, but corresponding support was lacking among stakeholders with the needed "influence."

Sometimes stakeholders at tribes are enthusiastic about participating in a research project because they want to share successful approaches with other tribes. For example, in a study of family violence in Indian Country, one tribe had developed a model approach that included legislation identifying family violence as an offense and implementation of effective policies and procedures for tribal police and courts—mandatory arrest of perpetrators, use of male-female police teams responding to family violence complaints (Hillabrant, Brown, Colhoff, & Earp, 1994). In the WtW evaluation, a tribe had developed a model approach to child support enforcement (CSE) which involved close collaboration with states to identify noncustodial parents who were employed but were not providing support for their children and to garnishee the wages of persons who refused to comply with tribal court orders to provide child support (Hillabrant, Rhoades, Pindus, & Trutko, 2001).

Longitudinal research and studies that involve data collection for six months or more can face additional problems including changes in tribal administration and changes in program staffing. Changes in tribal administration (e.g., new chairman, chief, governor) or newly elected tribal council members may view with suspicion research approved by a prior administration. Soliciting and obtaining approval of proposed research from a wide range of stakeholders can circumvent or minimize the effects of changes in administration. Effects of changes in program staffing on a study can range from minimal to catastrophic, depending on the nature of the research. Frequently, new staff must be trained to use or interface with the study protocol.

Ethical Problems and Issues

In general, research in Indian Country may have neither more nor fewer ethical problems and dilemmas than research conducted elsewhere. Still, issues such as cultural competence, relatively high rates of poverty and illness, and associated deficits in infrastructure (e.g., public transportation, plants and facilities, telecommunications) can exacerbate ethical problems and dilemmas.

University graduate training programs teaching research ethics may cover federal regulations and procedures associated with IRBs and OMB as well as regulations governing the care of animals in research (Health Research Extension Act of 1985); however, it is difficult for such training to focus on ethical issues and problems associated with persons who might come into contact with the research but who are not participants. Also, it is difficult for ethics training to address problems where the researcher's actions must balance immediate costs against potential greater costs. This paper concludes with discussion of such a problem.

Already discussed in Vignette 3 is the allegation of on-the-job substance abuse by a treatment program director. Another example involves the evaluation of a Head Start program producing exceptional benefits that was housed in a building that represented unacceptable risks to the children it served (see Vignette 4). The evaluators were confronted with the choice of reporting the violations, likely to result in the suspension of the program, or passively acquiescing in the continued exposure of the children to the risks associated with an unsafe building.

Making judgments about ethics and values can be challenging to researchers working in Indian Country because of potentially conflicting roles and circumstances, such as:

- If the researcher is not a member of the tribe participating in the study, he or she may be unfamiliar with critical values and expectations pertaining to ethical issues.
- The sponsor of the research may have agendas, rules, and expectations that are different from or in conflict with those of the tribe(s) participating in the study.
- The protection of study participant confidentiality may conflict with protection of study participants from abuse, family violence, or other threats.

In such circumstances, it is prudent for the researcher to seek guidance from the project advisory committee, the research sponsor, and/or legal authorities without disclosing information that would violate the identity of the research participant(s) or violate the confidentiality of participant data.

Vignette 4. Ethical problem: Closing an excellent Head Start facility.

The national Head Start program conducts rolling compliance reviews of local Head Start facilities to ensure that the programs protect the health and welfare of the children served. One of the program requirements is that no Head Start facility be located in a building with major building code violations. Conducting site visits at several facilities on a reservation, researchers found, with one exception, that each facility met or exceeded all Head Start program requirements. The children attending these programs were clearly flourishing, and entire families were benefiting from the program. One facility, however, was located on the second story of a wooden building that had multiple building code violations, including insufficient numbers of fire extinguishers and smoke detectors. Program staff were aware of the code violations; however, there were few alternate facilities available on the reservation that could be used by the Head Start program, and tribal officials had not responded to requests for better facilities.

The researchers did not want to jeopardize the operation of the clearly successful program. Options discussed included ignoring the code violations, urging program staff to continue their efforts to secure an alternate facility, and reporting the infractions to Head Start headquarters in Washington.

After a brief discussion, the study team concluded that failure to act, in this case, would subject the children participating in the program to unacceptable risks. Consultation with Head Start headquarters resulted in an order that the tribe immediately suspend operation of the program at the dangerous facility. This suspension stimulated tribal officials to action. Within a week, the tribe was able to make available a building that complied with Head Start regulations and the program resumed operations.

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Cultural Competence Approaches to Evaluation in Tribal Communities

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Abstract

Disability research and evaluation in Indian Country are rare and have generally been viewed with suspicion by both rural reservation-based and urban tribal communities because designs, procedures, instruments, and interpretation and dissemination of outcomes have often been developed or selected without regard for potential cultural conflicts. This paper explores the implementation of a national evaluation in eight tribal communities that obtained grants to establish systems of care for children with serious emotional disturbances and their families. The congressional mandate to participate in the national evaluation has resulted in tribal communities taking a step into the world of research and evaluation. Some of the challenges and successes these tribal communities have experienced through their participation in the national evaluation are explored.

In the year 2000, American Indians and Alaska Natives (AI/AN)[1] represented nine-tenths of 1% of the general U.S. population (U.S. Census Bureau, 2002); however, children and adolescents (under 15 years) in this population represent a greater proportion of the total population (33%) as compared to 22% for the general U.S. population (Hodge & Fredericks, 1999). It is important to note that AI/AN children and adolescents have been identified as being at a higher risk for mental disorders, depression, substance abuse, dropping out of school, delinquency, suicide, and homicide (in particular through vehicular accidents) than other ethnic minority groups and the general U.S. population (Nelson & Manson, 2000). It has also been suggested in the literature that these AI/AN incidence rates will increase with age at an accelerated rate as compared to all other racial or ethnic groups in the United States (Barlow & Walkup, 1998; Dion, Gotowiec, & Beiser, 1998; Goodluck & Willeto, 2000; Middlebrook, LeMaster, Beals, Novins, & Manson, 2001). It is clear that AI/AN children and families are in need of social and mental health services; however, determining the actual nature of a behavioral, emotional, or developmental disability is

[1] The term American Indians/Alaska Natives (AI/AN) is not meant to homogenize individuals from distinctly different cultures into a single ethnic group; rather, it is the current term used to represent more than 500 federally recognized tribes, including approximately 2.4 million American Indians and Alaska Natives. Each of these sovereign nations has distinct languages, religious beliefs, values, and cultural, social, and political histories. With apologies, the terms AI/AN and AI will be utilized throughout this manuscript as an attempt at brevity.

fraught with challenges rooted in the sociological, cultural, and political histories of AI/AN people themselves and their experiences with psychological and evaluation research.

To further exacerbate the challenges evaluation researchers face, services and research in Indian Country (urban and reservation tribal communities) have been noted throughout the literature as being based in western psychological theory, which is contrary to the value structures and worldviews of these tribal communities. Issues such as tribal sovereignty, tribal government permission to conduct research, data ownership, isolation, cultural barriers, and methodological and dissemination issues (Ericksen, 1996; Manson, 1997; Mihesuah, 1993; Stubben, 2001; Trimble, 1977) continue to plague service delivery and research and evaluation efforts with this population. Today we continue to ask questions such as: "What services?" "Where should services be provided?" "How should service be provided?" "Who should provide services?" "Are services culturally appropriate?" "Are services effective?" "Who are the children and families being served?" "What are children and families experiencing?" and "How do children and families change across time?"

This paper will provide a brief overview of psychological and evaluation research in Indian Country, describe service programs, and offer examples of how current tribal community recipients of a services and evaluation grant program, the Comprehensive Community Mental Health for Children and Their Families Program, are dealing with the challenges of conducting evaluation research in their communities. Using descriptive data collected through the national evaluation of this grant program, it will discuss how these and other findings may be influenced by historical, cultural, and other factors.

Only a few tribal or regionally specific community studies (Beals et al., 1997; Cross, 1986; Novins, Duclos, Martin, Jewett, & Manson, 1999) and a handful of larger scale studies have been completed with the AI/AN child and adolescent populations (Beiser & Attneave, 1982; Cummings, Ireland, Resnick, & Blum, 1999; Dion, Gotowiec, & Beiser, 1998; Mitchell & O'Nell, 1998; Roy, Chaudhuri, & Irvine, 1970; Sampath, 1974; Shore, Kinzie, Thompson, & Pattison, 1973), raising at least as many questions as they attempted to answer. The largest and most recent study, which included 13,454 AI/AN children, concluded that "the connection to family remains a consistently powerful factor in the lives of these youth" (Cummings et al., 1999, p. 38). We will see this theme recurring throughout our discussion, revealing some of the many and significant meanings of family relationships in Indian Country and their implications for services, research, and evaluation.

The few smaller regional or tribal-specific studies often cited in the literature did result in raising an awareness of the "handicapping" and assessment issues with the AI/AN child and adolescent population. For example, early on, researchers found that as many as 75% of AI/AN children living in boarding schools have experienced school-related social or emotional problems (Dlugokinski & Kramers, 1974; Kleinfeld & Bloom, 1977), and Ramirez and Smith (1978) noted that as many as 38% of American Indian children in Bureau of Indian Affairs (BIA) (non-residential) schools were handicapped. Dion, Gotowiec, and Beiser (1998) found that both non-Native children and their parents rated themselves higher on depression than did AI children and their parents. However, the teachers of AI children had a tendency to assign these children higher depression and conduct disorder ratings than non-Native children. Fisher, Bacon, and Storck (1998) attempted to address the methodological issues in urban-rural comparisons by examining teacher ratings in these settings, finding that although American Indian youth have higher levels of internalizing and externalizing behaviors (e.g., depression and conduct disorder) than Caucasian youth in the same rural community group, differences are much less general and pronounced than previous research suggested. Additionally, the disproportionate

diagnosis of psychosis, mental retardation, and learning disabilities among AI/AN children, both in the hospital and public school systems, has long been noted in the literature (Fritz, 1976; LaFromboise & Plake, 1983; O'Nell, 1989; Roy et al., 1970).

Though the research cited above certainly provides information that may be useful to many psychologists and service providers, the concept of "disability" has little meaning in AI/AN communities where there is typically no distinction among cognitive, emotional, physical (developmental delays) and spiritual concerns or illness (Adair, Deuschle, & Barnett, 1988; Barlow & Walkup,1998). Furthermore, the concept of illness (cognitive, emotional, physical, and spiritual) is often grounded in a relational worldview that is cyclical in nature and identifies the individual with an illness or disability as being "special" (Cross, 1986, p. 11) or as having been gifted with special abilities or personality characteristics. Therefore, words such as "disabled" and "handicapped" impose a worldview that conflicts with that of many AI/ANs. Those children and adolescents who experience serious emotional or behavioral problems, or both, are often considered to be passing through a developmental stage, and rather than intervene, parents and families tend to assume a "wait and see" approach. In order for program evaluation research to be effective and accurate, it must address underlying issues of the definition of, and expectations for, behavior and change among program participants.

Systems of Care in Tribal Communities

A first step toward identifying challenges that AI/AN children and families face, and toward identifying strengths and weaknesses of service systems available to them, is to understand clearly and comprehensively the roots of the key system from which these children emerge: the family system. Red Horse, Lewis, Feit, and Decker (1978) provide remarkable insight into the extended family system, identifying three primary differences between AI/AN families and White European or Caucasian families. The first difference they note is in the definition of extended family. The White European or Caucasian definition identifies the extended family as three generations living in the same household, whereas in AI/AN cultures it is defined as a village-type network construct which has a significant impact on behavior and socialization processes. Secondly, in AI/AN tribal communities this extended family structure transmits culture and conserves family patterns, which in turn contributes to identity development. Finally, according to Red Horse et al. (1978), the family promotes accountability in that it sets standards and expectations which then maintain the wholeness of the group through the enforcement of values. It is interesting to realize that we have come around full circle: from the establishment of reservations and the imposition of a nuclear family model which was used as an instrument to "civilize" tribal people and assimilate tribal culture, to modeling community mental health services after AI/AN systems of care (Medicine, 1981, p.14). Unfortunately, until recently, re-awakening and operationalizing tribal systems of care in Indian Country has lacked organizational, political, and financial support. Instead, as in years past, these systems operate quietly underground and often go unrecognized or untapped as resources.

Scattered throughout the literature are "gems of wisdom" (Cross, 1986; LaFromboise, 1988; Medicine, 1981; Red Horse, 1980; Swinomish Tribal Mental Health Project, 1991; Trimble, Manson, Dinges, & Medicine, 1984), each of which has offered "road markers" for service development and delivery to AI/AN populations. Respected American Indian leaders in the field direct us to turn to the extended family unit to answer questions about service development. Bea Medicine (1981) summarizes the discussion of future directions in the field with, "We should be discussing the underlying orientations, beliefs, and kinship systems of a variety of Indian families" (p. 13). This suggests that we need to pave our services

highway with those family-based cultural values, beliefs, and kinship systems that are specific to the tribal community and to those families who may depart from the "norm" in their community. The concepts of systems of care and the "wraparound process" (interagency services addressing emotional, physical, mental, and spiritual needs of the child and family, from therapy to respite care), were initially introduced by Stroul and Friedman (1986); however, as Debbie Painte (in Kendziora, Bruns, Osher, Pacchiano, & Mejia, 2001) noted, the wraparound concept was not a new concept in Indian Country but "is a re-visiting of our former village and clan and tribal structures" (p. 31). She further explained how the wraparound process represents a return to traditional ways. "This whole cultural erosion that we've had really has led to some of the . . . challenges that we face. We needed to find a way to rebuild those structures that we had for our families before. When we heard about Wraparound, it clicked. This is how we bring those interventions back. Those cultural ways that we had. This is the validation of our culture" (p. 31). Most, if not all, AI/AN individuals, families, and communities would concur.

Federal funding began in 1993 for grant communities to develop "systems of care" for service delivery to children and adolescents with serious emotional disturbance and their families through the Comprehensive Community Mental Health Services for Children and Their Families Program. This program, supported by the Center for Mental Health Services (CMHS) in the Substance Abuse and Mental Health Services Administration (SAMHSA), has a strong commitment to program evaluation and to building evaluation capacity in grant communities. This federal initiative has supported the development of systems of care in 43 states, including eight AI/AN communities. The initiative includes a mandated national evaluation component that follows congressional efforts toward program accountability.

The congressional mandate that federally funded programs must be evaluated, as well as the program's investment in building community capacity for evaluation, have resulted in grant-funded tribal communities taking a step forward into the world of research and evaluation. The following section provides a brief description of the tribal communities funded by CMHS to develop systems of care. It will be followed by a description of the national evaluation developed for CMHS-funded grant communities and will include a description of evaluation activities in these communities that include efforts to implement the national evaluation in tribal settings, as well as efforts to develop community-specific evaluations that address unique characteristics of tribal programs not captured by the national evaluation.

Among the eight tribal communities receiving CMHS funding to develop and implement systems of care since 1993, two communities had previously participated in CMHS Circles of Care planning grants (Sault Ste. Marie and Oglala Lakota). Together, these two federal initiatives offered financial support that, for the first time, provided opportunities to "reawaken" historically and culturally based systems of care within these tribal communities. The first American Indian tribe to receive funding by CMHS was the Navajo Nation, in 1994, through its K'é project. In subsequent funding cycles seven additional tribal programs were funded: in 1997 Kmihqitahasultipon (Passamaquoddy Tribe, Maine), and Sacred Child (Inter-tribal in North Dakota, South Dakota, and Montana), in 1998 Mno Bmaadzid Endaad (Sault Ste. Marie Tribe of Chippewa Indians and Bay Mill Anishnabe tribal communities, Michigan), and With Eagles' Wings (Northern Arapaho and Eastern Shoshone, Wyoming), and most recently, in 1999, Yuut Calilriit Ikaiyuquulluteng (Yukon-Kuskokwim Health Corporation, 58 villages, Alaska), AK-O-NES (United Indian Health Services, Humboldt and Del Norte Counties, California), and Nagi Kicopi (Oglala Sioux, South Dakota).

In 2000, Terry Cross and his colleagues conducted a series of focus groups and presented a number of common themes inherent in the structures of five of these tribal programs. They included the use of 1) extended family; 2) traditional teachings; 3) culturally specific approaches; 4) cultural restoration (mentors, crafts, language); 5) methods that promote healing of Indian identity and self efficacy; 6) methods that build connections to community, culture, group, clan, extended family; 7) methods that are based in spiritual beliefs and support systems; 8) approaches incorporating elders or intergenerational approaches; 9) individual and family skill building for living in two cultures; 10) traditional helping values (e.g., 24-hour staff availability); 11) conventional and cultural methods to recognize and treat historic cultural, intergenerational, and personal trauma; 12) approaches that strengthen or heal the community; 13) incorporation of a respect for diversity within the tribe and within the service array; and finally, 13) conventional services (individual and family therapy, and health care services) (Cross, Earle, Echo-Hawk Solie & Manness, 2000, p. 48).

The eight tribal grant communities have other similarities, such as their organizational structures. The systems of care in some of these communities are grounded within programs offered historically by their respective tribal, social, and health programs and sponsored by their tribal governments (Navajo, Passamaquoddy, and Oglala Lakota). The other five programs (Sacred Child, Wind River, Sault Ste. Marie/Bay Mills, Humboldt, and YKHC) have an intertribal structure based on shared resources and geographic location, and have had an intertribal approach to the development of services and sponsorship for funding. They may be co-utilizing health clinic services under a single health care provider, such as United Indian Health Service (for Humboldt and Del Norte counties in northern California) and the Yukon-Kuskokwim Health Corporation, or have joined together to access funding because they are geographically close to one another, as are the Sault Ste. Marie Tribe of Chippewa Indians and the Bay Mills Tribe of Anishnabe (Ojibway), both located in the northeastern end of the Upper Michigan Peninsula, and the Northern Arapaho and Eastern Shoshone Tribes that share the Wind River Reservation in Wyoming.

For the most part, many of these tribal communities share similar challenges based on their geographic isolation, unavailable or unreliable transportation, severe weather, large geographic distances in their service delivery areas, and having access to few if any community-based mental health services within a radius of forty to a hundred miles of their communities. This is in contrast to some of the other tribal grant communities that are seemingly surrounded by the general population and therefore have limited (though possibly not culturally appropriate) services for their children and adolescents.

These eight tribal and intertribal programs are fairly representative of the diversity in reservation and urban service delivery settings across the country in terms of their levels of self-identified acculturation/assimilation. The differences between and within these tribal grant communities are clearly evident in both the service delivery structures and the arrays of services they have established and are demonstrating. Of great interest is the development of culturally appropriate assessment instruments and the use of unique treatment methods that are major contributions to the field. For example, the Navajo tribal grant community's service delivery structure is based on "K'é [which] means to have reverence for all things in the universe and to maintain balance and harmony by acknowledging and respecting clan and kinship" (Cross et al., p. 32). Accordingly, they developed the position of a "traditional behavioral management specialist" that is grounded in their traditional clan system while utilizing a Navajo approach to counseling and to coordinating other traditional treatments or ceremonies as needed and as identified by the healers and desired by the families themselves.

In contrast, both the service delivery structure and the types of services provided in the Passamaquoddy tribal community are focused on providing multiple levels of interventions. Younger children, families, and the community itself are provided with opportunities (services) to reintegrate Passamaquoddy culture into their lives. This in effect works toward reestablishing tribal values and traditions, ultimately assuring the continued survival of tribal culture while reframing it as a viable resource or system of care for children and their families. Many of the mothers in the study were formerly enrolled in services themselves, providing a longitudinal, multi-generational aspect to the project.

The Sault and the Bay Mills tribal communities seek to enact a "cultural renaissance" and are committed to the incorporation of Anishnabe (Ojibway) cultural values as a critical component of system development, system reform, and system evaluation. A unique focus of this project is its partnership with the Hiawatha Behavioral Health (community mental health center) in order to address service delivery issues. This is a highly unusual undertaking in Indian Country, as the partners must collaborate on administrative and programmatic responsibilities. The project strives to support and reclaim the tribe's language and other cultural practices as part of a movement towards overall improved mental health of tribal children and their families.

In response to distinctly different service delivery issues and needs, the primary goal of the Sacred Child program is to reduce the high number of American Indian children who are sent to residential facilities, and to assist in the reentry of those who are returning from out-of-community placements. Like the program of the Passamaquoddy tribal community, the Sacred Child program is strongly grounded in family-centered philosophy and the staff firmly believes that services need to address the family as a whole unit. They have developed a tool for the extensive assessment of child and family needs that is focused on a treatment planning model which utilizes twelve distinct "life domains": family, social, behavioral, educational, safety, legal, health, crisis, spiritual, cultural, financial, and housing. Families choose their priority domain(s), with community-based care coordinators assisting in establishing the wraparound process to develop their own family-based goals. The program's process also incorporates important American Indian traditions of group healing and community-based resources.

The Nagi Kicopi "Calling the Spirit Back" program has made extensive efforts to reflect the Lakota healing and cultural practices as the foundation of the service delivery model, rather than attempting just to integrate these practices into a service delivery model grounded in western therapeutic practices. These efforts were initially supported by a Circles of Care grant that provided an opportunity for the grant community to identify existing systems of care and explore the gaps in services (through a series of community focus groups and parent, youth, teacher, and provider focused surveys) and the cultural shortcomings of these services. This community also developed the Tiwahe (family) advocacy group, which in turn assisted in the development of a culturally grounded services curriculum and intake assessment instruments based on functional knowledge of Lakota culture. The intake instrument is used as a tool for the extensive assessment of the youth's and family's level of Lakota cultural knowledge which, in turn, is used to develop a culturally appropriate treatment plan. Following referral, this community has an extremely detailed four-phase enrollment process that includes preenrollment, enrollment, and initial assessment and provides for a fully informed consent process. A purification ceremony is held that brings the family and extended family together to determine a course of action. The Lakota system of care at Nagi Kicopi has become a family- and community-based intervention that is guided by the care coordinators who assist families in reclaiming their Lakota language, values, and beliefs through participation in traditional healing ceremonies.

Evaluating Systems of Care in Tribal Communities

The national evaluation was initiated in 1994 and developed for use in a broad range of communities across the United States that provide services to children and families from all walks of life. Across all cycles of program funding, the national evaluation has included four components implemented in each funded community: 1) the assessment of infrastructure and service system development (system level assessment), 2) description of the children served by the program, 3) assessment of the service experience and longitudinal outcomes for children for up to three years, and 4) assessment of services provided and related costs as recorded in management information or billing systems to the extent available in each community. Assessment of system development and assessment of costs and services are conducted by the national evaluation team with assistance from the grant community. Communities are financially supported through their grants to collect descriptive information and to conduct the longitudinal outcome study by implementing national evaluation protocols locally with guidance from the national evaluation team.

The national evaluation protocol includes collection of descriptive, demographic, and diagnostic information about each child at intake, and longitudinal data for a subset of children and adolescents. Data for the longitudinal outcome study are collected every six months for up to three years through interviews with caregivers and youth aged 11 years and older. Among currently funded grant communities, data are collected using four clinical measures: Child Behavior Checklist (CBCL; Achenbach, 1991a), Youth Self-Report (YSR; Achenbach, 1991b), Child Adolescent Functional Assessment Scale (CAFAS; Hodge, 1990), and the Behavioral & Emotional Rating Scale (BERS; Epstein & Sharma, 1998); four functional measures that assess children's living situations, education, delinquent behaviors, and substance use (these last three measures are administered only to youth); three family measures that assess adequacy of family resources (Family Resource Scale, FRS; Dunst & Leet, 1987), family functioning from the caregiver's and youth's perspectives (Family Assessment Device, FAD; Epstein, Baldwin, & Bishop, 1983), and caregiver strain experienced as a caregiver to a child with serious emotional disturbance (Caregiver Strain Questionnaire, CGSQ; Brannan, Heflinger, & Bickman, 1998); and two service experience measures to assess which services were received and in what settings, and satisfaction with the cultural competence of services from the caregiver's and child's perspectives.

Implementing a national evaluation protocol in diverse communities raises issues of cultural competence because these protocols were not developed with a particular community's needs and circumstances in mind. Indeed, many communities have argued that the national evaluation itself is incongruent with the system-of-care principle of cultural competence. For example, assessment at the service system level using a global protocol may obscure some of the unique factors that influence characteristics of service delivery in specific communities. In addition, conducting a longitudinal study is generally an intensive and difficult process and must be tailored to the unique circumstances of the community within which it is conducted without compromising the goals of the research. Because this study has a lengthy protocol that may include questions that have different meanings in different cultural contexts, are inappropriate to ask of certain people, or require extensive introduction or debriefing, considering how to introduce the evaluation to the community, how best to recruit participants, conduct interviews, and maintain contact with families over time are issues that must be addressed with each community.

System Level Assessment

Assessing system development at the infrastructure and service delivery levels in

relation to the principles that guide systems of care (family-focused, individualized, culturally competent, collaborative/coordinated, accessible, community-based, least restrictive) involves conducting semistructured qualitative interviews (every 12 to 18 months) with a cross-section of administrators, service providers, and families involved in the service system in each community. A draft report is developed, reviewed by the community for accuracy, revised, and then disseminated.

These system-of-care assessments for the national evaluation have been conducted in all tribal communities except those most recently funded, where the assessment process is in the initial planning stages. Interviewer training was conducted by tribally identified and nationally recognized trainers in preparation for the system-of-care site assessment visits. This training was held to give interviewers a historical perspective on the strengths of American Indian families, the breakdown of American Indian communities resulting from dominant culture oppression, and the renewal and healing strengths of today's families and communities. Information was also presented regarding life differences in worldview, communication styles, customary behaviors, and cultural assumptions and values. Medicine Wheel Teachings were also presented as well as interactive experiences in the use of oral traditions and story telling.

Communities also conduct culture-specific orientations for interviewers as they enter the community and before any interviews are conducted. For example, site visits have been extended by one or more days so that interviewers have adequate time to become acquainted with historical issues and their impact on tribal members, participate in traditional activities and ceremonies (at the invitation of community members), take tours of local historical and contemporary points of interest, and be included in informal conversation with community members and program participants where culture-specific information has been shared. This culture- and community-specific evaluation training has occurred before any evaluation training or data collection interviews have been conducted.

In order to obtain meaningful information about a service system, it is important that appropriately knowledgeable persons are interviewed. Although it is the community's role to identify individuals who should be interviewed, factors such as language, political alliance, the appropriateness of individuals from outside the community conducting interviews, and the appropriateness of posing certain types of questions to certain community members or to healers may have an impact on the selection of members of the community who are interviewed. In addition, lack of familiarity with culture- or community-specific protocol ultimately may have an impact on the success of the interview process. Such protocol might include, for example, unique elements of verbal and nonverbal communication, and impacts might be related to the dissonance of perspectives of persons unfamiliar with a specific AI/AN culture and members of that culture, limited personal understanding of historical and inter-generational trauma and fears associated with participating in research, fears associated with differential types of responses and consequent continuation of or access to services and supports for services by tribal communities.

The system-level assessment of the national evaluation offers some potential benefits for grant communities to build into their systems a community-based self-evaluation which gives voice to those receiving services. The issue critical to the success of this process is in building capacity and in understanding the process itself with both the service providers and those receiving the services. One way this may be achieved is by providing opportunities for the process to become more participatory. Although communities currently determine who should be interviewed, contribute to the completion of the report, and are encouraged to utilize and disseminate the report, engaging the community (or parents and families) in determining some of the interview questions, utilizing individuals from the community as

interviewers, promoting greater involvement by the community in the development and dissemination of the report and, most importantly, in strategizing how to utilize the information to enhance and improve services would contribute to building evaluation capacity. System-level assessments for the national evaluation have been conducted in all tribal communities except those most recently funded, where the assessment process is in the initial planning stages. To facilitate this process, some communities provide a type of cultural immersion training to individuals who come into their communities or provide a community "presence" via the participatory role of elders.

Longitudinal Outcome Study

Although the national evaluation protocol for the longitudinal outcome study is the same for every community and a set of guidelines is provided for the implementation of the evaluation, community-level differences do exist in the overall structure of the evaluation teams and some differences exist in how communities deal with geographic, cultural, and other factors. For example, the Wind River, Sault Ste. Marie/Bay Mills, Humboldt, and YKHC projects all conduct their evaluation as if they are serving one large tribal community with multiple service delivery offices. This provides some advantages, such as maintaining a central data collection and management system and assuring consistent training of evaluation team members, and some disadvantages, such as use of a generic implementation protocol for people who may have distinctly different cultures and provision of data findings based on the aggregate versus community-level experience. The Sacred Child project, in contrast, subcontracts data collection to each of the four participating tribes, although a central evaluation coordinator provides data collection training and collects and consolidates the data into one data bank that represents all four tribal communities. The Sacred Child project's challenge is in administering this intertribal project in such a way that it provides some autonomy to allow for a more culturally appropriate evaluation implementation while collecting the data in a centralized manner.

The K'é project of the Navajo Nation developed a comprehensive cultural self-assessment tool which was completed with each participating family. This cultural assessment tool gathered basic information about a family's level of understanding and involvement in traditional beliefs and practices, providing a cultural framework for treatment plan development. The K'é project was faced with a need to address the language and translation issues associated with implementing the national evaluation protocol in communities where English was the second language for some adult caregivers as well as for some of the children and adolescents. Further, because many family members speak only the Native language, accurate and understandable translation was difficult if not impossible, as many of the items on the instruments in the national evaluation protocol did not have similar concepts in Navajo. The YKHC project in the Alaskan Native villages and the Nagi Kicopi project also face some of these challenges as they implement the national evaluation in their communities.

The Passamaquoddy evaluation team was faced with dealing with the contrasting values of traditional child development research methodology, which emphasizes the individual child and caregiver, and Passamaquoddy culture, which is family-oriented. The evaluation team has attempted to deal with this cultural incongruence by modifying the national protocol in a number of ways. First, the family is enrolled in the evaluation, so that one child is not targeted as a "problem child." Therefore, caregivers may complete child-specific questionnaires such as the Restrictiveness of Living Environments Scale (ROLES; Hawkins, Almeida, Fabry, & Reitz, 1992) or the CBCL for more than one child in the family. In addition, for caregiver-specific measures (e.g., the CGSQ or the FAD), the caregiver is asked to rate the impact of all of the children's needs on both the caregiver and the entire family unit. This provides an

additional reporting burden for the parent or caregiver respondents and causes some unique interpretive challenges in analysis of the evaluation data; however, this approach responds to some of the culture-specific needs of the community. This community has also developed a comprehensive local-level evaluation initiative which includes a parental satisfaction questionnaire, a documentation process for social and cultural activities, and a series of qualitative community-wide interviews (documenting community and family perceptions of change). Qualitative reviews of 30 case records and the development of a number of family case studies (which will not be representative of a particular family unit but rather a compilation of characteristics in order to preserve confidentiality in this small community) complete the local assessment package. Development and implementation of the national evaluation are often considered the main challenges tribal grant communities face and may overshadow challenges related to dissemination. The Passamaquoddy evaluation team made early efforts to provide feedback to community members from the data they had collected. They used a traditional research conference presentation style and provided findings in the aggregate. Family members found the presentation difficult to follow and relatively useless. The evaluation team had to reconsider the utility of the data at the community level and develop new methods for dissemination.

The Sault Ste. Marie community is utilizing what is perhaps the first computerized cultural assessment tool to assess a participant's degree of identification with the culture and values of the Anishnabe (Ojibway) people. This tool is used by the Mno Bmaadzid Endaad project to begin to evaluate the interaction between children's and the caregivers' identification with the culture and the services provided by project staff. In addition to this tool, the project is using a computerized version of the Diagnostic Interview Scale for Children (DISC-IV; Shaffer, Fisher, Lucas, & The NIMH DISC Editorial Board, 1998).

The Sault community also initiated a series of focus groups with the evaluation team and service providers to develop a clearer understanding of how well-being might be conceptualized among those served in the system of care and how this well-being might be assessed using an evaluation framework. These focus groups stemmed from conversations held among evaluators of tribal grant communities who were struggling with the concept of "functional impairment" and its application to AI/AN children. This focus group work had not been completed at the time of this report. Unlike the Passamaquoddy community, the Sault grant community has been successful in using data drawn from the national evaluation at the community level. Presentations are made by the evaluator or the project director to local advisory boards, family groups, and service providers. This information is used to enhance the service delivery system and to obtain feedback on the evaluation process and program in general.

The Sacred Child program, with its four distinct evaluation teams, conducted a thorough review of all of the national evaluation measures, made some modifications to assure a more culturally appropriate evaluation, and provided critical feedback to the national evaluation team as well as to CMHS. Upon initiating the national evaluation protocol, they found the estimated time needed to complete the caregiver packet exceeded two hours and often took four or more hours. The parents (or caregivers) experienced the evaluation as a large time burden and were often overwhelmed by the sheer volume of questions. The evaluation team decided to use clinician reports to complete the CAFAS in place of the longer caregiver interview. Though this clearly had an impact on the time needed to complete the caregiver packet, the grant community faced additional challenges regarding time and the overall comfort level caregivers experienced when completing the interview. The grant community made minor modifications to items that were potentially confusing (e.g., contained double negatives),

generated alternatives for items with multiple meanings (e.g., "seeing things" might be interpreted as "having visions"), and offered alternative language for words not commonly used in their community. Many of the changes this grant community made have been shared with other grant communities through national evaluation team members. In addition, the Sacred Child Project was identified as a CMHS "host" community, functioning as an informal mentor to more recently funded tribal grant communities that are dealing with cultural concerns as they apply the national evaluation protocol.

The Nagi Kicopi project has effectively utilized its experience as a Circles of Care grant community to inform and influence the evaluation of its more recently funded system of care. This grant community developed a complex process to explore the meaning of health among Lakota children and families. They used this process to develop an assessment tool that is specifically for assessing functioning from a Lakota cultural framework. The project is also considering expanding the Multi-Sector Service Contact (MSSC; ORC Macro, n.d.) instrument used to collect information about services received, to incorporate their culturally specific service delivery structure and to assess whether these services are meeting the needs of the child and family. As with the K'é project and the Sacred Child Project, wording for some individual items is modified as needed. In addition, portions, if not all, of the interview (and introduction protocol) can be offered in the Lakota language through on-the-spot translation.

These are a few examples of how tribal communities participating in the Comprehensive Community Mental Health Services for Children and Their Families Program have attempted to make the longitudinal outcome study of the national evaluation more consistent with the cultural values of their communities and the overall goals of their systems of care. It is important to note that while the tribal grant communities have made significant strides towards implementing the national evaluation, the national evaluation team itself is pilot testing modifications made in response to some of the broader concerns of these grant communities. The process that led to the development of modifications involved addressing tensions and evolving awareness regarding the conflicting needs of the communities, the federal funder, and the contracted evaluator. The need to address this conflict with the national evaluation was further heightened with the funding of additional tribal communities in subsequent funding cycles. Of particular concern among all tribal communities (and addressed, in part, by the Sacred Child program) is the length of time required to complete an interview with caregivers in their community. Evaluators report that cultural protocols, such as sharing "small talk" and listening to stories told by caregivers, lengthen the interview time, thereby creating an undue burden on caregivers.

As discussions regarding implementation of the national evaluation developed, the tribal grant communities recognized the importance of the granting agency in determining modifications to the national evaluation, and collectively directed their concerns directly to CMHS. The feedback obtained through this process provided valuable information to assist CMHS and the national evaluation team in developing some alternatives for evaluation implementation with the concerns of the tribal communities in mind. These alternatives have become identified as the "flexibility plan," available to tribal grant communities as a pilot test for future evaluations.

Of interest in this process is the change in perceptions of the national evaluation team among tribal communities, which resulted in a more collaborative approach to implementing the national evaluation. This process serves to remind evaluators and researchers that tensions signal that there are important issues to address that will not disappear if they are ignored. This tension can be utilized as an opportunity to return to the drawing board and

collaboratively address the situation. Further, it is important to note that often fears associated with the evaluation process are in direct proportion to the personal responsibilities of each participant. For example, tribal grant communities have a responsibility to their children, families, and communities as a whole, while an evaluation contractor has responsibilities to a client (in this case the federal government), and the funding agency has responsibilities to Congress.

The flexibility plan provides tribal communities with the option of excluding the Child Adolescent Functional Assessment Scale (CAFAS; Hodges, 1990) and the Caregiver Strain Questionnaire (CGSQ; Brannan, Heflinger, & Bickman, 1998) or the Youth Self-Report (YSR; Achenbach, 1991b) and Family Resource Scale (FRS; Dunst & Leet, 1987) from the interviews. In return, tribal communities agreed to work on the development of a culturally competent instrument that could be used across tribal communities to assess functioning. Thus far, two tribal grant communities have opted to drop the CAFAS and all communities are utilizing the CGSQ, YSR, and FRS. If participant burden has an impact on enrollment or attrition rates, some tribal communities may decide to drop the CAFAS from the protocol. Although few communities have chosen to adapt the evaluation protocol, evaluators and administrators from the tribal communities initiated conversations about how to best develop a new evaluation tool. They considered development of a universal tool and community-specific tools. Some communities, like Nagi Kicopi, had already developed a process and a draft tool. Others, like Sault Ste. Marie, initiated a series of focus groups (described above). All are continuing to work together to develop a survey instrument which will examine the processes of system development, implementation of the national protocol, and the processes of developing culturally specific instruments.

Community Empowerment in Evaluation

It is important to identify methods that not only empower parents, families, and communities but that enhance their capacity to conduct culturally relevant research and evaluation in their own tribal communities. The two primary methods that need to be highlighted are the use of community-based advisory committees and the establishment of a collaborative skill-building relationship with their evaluation team. The metaphor of putting Indian Country "behind the wheel" of the research-evaluation bus is an apt description of the potential this kind of collaborative work can have.

The Sault Ste. Marie project was the first tribal community to provide a model for other tribal grant communities, as they early on established an advisory committee that is representative of the communities that the grant serves. Many of the advisory committees assume responsibilities to provide staff with both programmatic and evaluation input and guidance. For example, some committees provide valuable staff feedback and direction on staffing (e.g., interviewers) for the national evaluation, cultural protocols needing to be addressed or developed, suggestions for motivating parents to participate (e.g., participant payments and participation in special activities), piloting or trying out the instruments (with volunteers from the community), topical focus group participation, presentation (topic, style, and content) feedback on data dissemination, use of evaluation data by clinicians, and presentations to families, tribal communities, tribal stakeholders, tribal business councils, and non-Indian stakeholders. The Oglala Lakota project grounded their development within the Tiwahe (family) advocacy group, which was instrumental in the many facets of the project's development from the beginning and continues to be utilized for multiple purposes as the needs and issues arise in terms of assessment, services, service delivery, local-level evaluation initiatives, and the national evaluation.

Additionally, as a result of the established relationships with certain faculty at the University of Wyoming, the on-site evaluator for the Wind River project incorporated a procedure to allow clinically useful information collected during evaluation interviews to be exchanged with clinicians identified by the family. This process allows parents or caregivers, as well as the children or adolescents, the opportunity to have their participation in the national evaluation be of use to them clinically, which makes participation in the evaluation potentially useful beyond the needs of the evaluation. In contrast to conventional evaluation and research relationships, this approach to establishing relationships among an evaluation team (both on-site and off-site evaluators), administration, parents and families, and the community—all within the framework of evaluation—promotes collaboration, cultural competency, and community empowerment while building evaluation capacity in tribal communities.

Continuing Challenges

Many tribal communities have tailored to the specific cultural needs and the varying levels of acculturation of their communities everything from the service delivery framework to the types of services available. Tribal grant communities funded by the Comprehensive Community Mental Health Services for Children and Their Families Program provide a powerful example of how systems can be developed or modified by community members to meet community needs. In addition, though the evaluation activities of these communities are far from perfect, the communities have made a good faith effort to involve themselves fully in national and local evaluation efforts. Though the systems are serving children and families and the national and local evaluation teams are collecting information regarding system development, child and family characteristics, and child and family outcomes, challenges still remain.

These communities are interested in demonstrating the efficacy and utility of the service delivery structure and culturally grounded treatment approaches to "outside" entities, which could provide financial sustainability following the end of the funding period. However, these cultural approaches, many of which are described above, are typically seen as suspect by funding agencies, since they fall outside the norm of other western-based service providers and systems in their states. The challenge these communities face and for which they need support is to gain recognition of the therapeutic value of these culturally specific services and service delivery structures, which in turn will generate opportunities for future financial sustainability. The research reviewed above indicates that it is not just the prevailing methods used to evaluate children and families that are inappropriate or inaccurate to fulfill this need, but also the underlying assumption of what it means to be "healthy." Though small changes made in the national evaluation protocol begin to address the needs of these tribal communities, the accuracy of this information in reflecting the true nature of the challenges faced by the children and the true nature of the changes they experience (which will ultimately be used to reflect the success or failure of a system) must constantly be questioned.

One challenge, which cannot be overcome in this project, is the need for these small communities to protect the confidentiality of the participants and the communities in general. Thus, data presented to the general public must be presented in aggregate form. This alone overshadows unique cultural characteristics of the children and families and the programs designed to serve them.

Of interest in the aggregate data are the significant gender, age, and income differences between the AI grant communities and all other CMHS grant communities. The AI grant communities tend to provide services to significantly more males (61.1%) than females (38.9%), with an average age of 10.4 years, in

contrast to the other grant communities that provide service to a larger population of males (69.76%) than females (30.24%), with an average age of 12.4 years. This would suggest that proportionately the numbers of AI male children and adolescents served are similar to the general population, although in AI communities they are served at a much younger age (10.4 years versus 12.4 years). This brings to the forefront issues associated with aggregating data with such diverse tribal communities. The targeted service population ages of at least two of the AI grant communities are much younger than their peer programs (as young as 6 in one community). This age difference clearly informs the types of services offered to children and families, and is likely to affect the overall rate of change children and families experience. This may impact the interpretation of "effectiveness" statistics that emerge locally or when compared to a tribal or national aggregate.

Custody status and living arrangements, factors typically examined across time as indicators of functioning (multiple changes considered a negative indicator, no change considered an indicator of stability), are examined at length in the national evaluation. Custody status is a highly sensitive variable in tribal communities where illness, alcoholism, death, and other factors may force a custody situation on a family. Actual living arrangements may be described and valued differently among tribal communities, particularly those where the "extended" family is considered the immediate family. Living in three or four different "households" in a given period of time may be considered a strength if a child is spending time with relatives and important family friends. Though standard analysis of living arrangement data might consider these moves a sign of instability, they may instead be a sign that a child has positive social relations, is able to adjust to multiple environments, or is playing a key role as family member or even caretaker. Furthermore, the rural or urbanized nature of a reservation or levels of acculturation may have further impacts on the distribution of children in different custody or living situations and on the overall interpretation of these data. Among children for whom living arrangement data are available, approximately 44% of children in tribal communities lived in two-parent households compared to about 30% of children from non-tribal communities. About equal percentages of tribal community and non-tribal community children lived in mother-only households (28%). A greater percentage of tribal community children resided with relatives (11.3%) than non-tribal community children (8.9%).

Referral source may provide an indication of the interagency nature of a system of care or may be indicative of previous service utilization by children and families referred to systems of care. Referral source information drawn from tribal (n = 412) and non-tribal communities (n = 3429) were obtained through the examination of client records. Fifty percent of all referrals in the tribal communities were made by the caregiver himself or herself. This is in contrast to the less than 7% of caregiver referrals to non-tribal systems of care. The self (child) referral for the tribal communities (3.64%) was also greater than the other grant communities' rate (1.1%). The largest referral source for all other grant communities was mental health agencies and clinics (28.8%), which is more than double the mental health referral rate for AI communities (11.2%). While it seems logical that the schools would be a large referral source (17.6% in all other grant communities), in the AI communities this rate was significantly lower (8.3%). In this same vein, the referral source from corrections agencies or facilities for the AI child or adolescent is ten times less (1.2%) than the referrals identified for all other grant communities (16.5%). Interpretation of these findings requires communication with the grant communities themselves.

Previous service utilization data indicate that children served in tribal systems of care are less likely than other children to have received services prior to entry to systems of care. Thus, these children may not have been in contact with mental health services and thus would not be referred by them. Schools in tribal

communities may not have personnel available to assess the service needs of children and therefore be unprepared to refer them to a system of care. Tribal systems of care may not have developed collaborative relationships with mainstream agencies and therefore may not receive referrals from them. It may be the case that historical, cultural, or economic factors influence the nature of relations that caregivers have with mainstream service systems, which results in a reduced use and trust of these systems. Other factors may also influence these differences. Factors such as previous service utilization or history with service systems may have an impact on the way children and families experience or respond to the systems of care set up in tribal communities.

The information presented above is drawn from descriptive data provided by caregivers or obtained from administrative records. At first glance it may be considered simply descriptive, with no inherent meaning or implication for interpretation of other data drawn for national evaluation purposes. It is clear, however, that even these few variables are likely influenced by cultural, historical, social, and other factors that are typically unique at a community level, and that will likely have far-reaching implications for the structure and effectiveness of the tribal community systems of care. It is important to note that many of the evaluation outcomes based on clinical, behavioral, and functional measures could be easily misconstrued or interpreted within a western theoretical model. From a tribal community perspective an entirely different, culturally grounded perspective could be drawn, which would be based on the knowledge of both the historical impact as well as contemporary issues obvious only to community members. Additionally, there are community level differences in interpretation, so results must be examined and interpreted by communities from their own knowledge of their community, their worldview, and other community-specific historical issues that may be relevant.

Summary

Comprehensive and culturally competent evaluation in AI/AN communities may become a reality as tribal communities are offered opportunities to assume leadership roles in this process. Funding provided through the Comprehensive Community Mental Health Services for Children and Their Families Program supports these eight tribal communities to step to the front of the room and reply to questions such as: "What services?" "Where should services be provided?" "How should services be provided?" "Who should provide services?" "Are services culturally appropriate?" "Are services effective?" "Who are the children and families being served?" "What are children and families experiencing?" and "How do children and families change across time?" Though these questions and the methods used to address them were not developed by tribal communities, they have given communities something to work with, react to, and modify, and in many instances have motivated communities to develop their own tools and methods based upon their own worldview.

Indeed, these tribal communities have provided us with a number of lessons learned. For example, the utilization of a broadly representative advisory committee composed of youth, parents, elders, community members, and community stakeholders provides significant culturally appropriate feedback and contributions not only to evaluation design, instrumentation, and implementation protocols, but also in the dissemination of the data to the community and other entities. Taking the use of an advisory committee a large step further, Nagi Kicopi's Tiwahe (family) advocacy group developed the programmatic framework, intake and assessment instruments, and service delivery curriculum. The Tiwahe continues to provide ongoing feedback to project staff, who rely on this group which serves as the community's "voice." Local-level evaluation protocols, cultural assessment instruments (such as Sault Ste. Marie's and Oglala Lakota's), community focus groups

(defining cultural wellness and other constructs), cultural protocols for interviewing families, and other qualitative and quantitative tribally developed measures are all excellent examples of the outcomes that are possible when tribal communities are empowered. It has taken decades for the scientific community to come to the realization that tribal communities can become empowered to identify their needs, determine a course of action, and take the necessary steps toward achieving the goals they have set for themselves.

What is truly exciting is that the current national evaluation design for the Comprehensive Community Mental Health Services for Children and Their Families Program provides opportunities for tribal communities to examine more closely culturally based traditional assessment, treatment, and healing methods as well as to build a skills-based capacity for research and evaluation. Stubben (2001) succinctly describes a culturally competent framework for working with and conducting research in AI/AN communities, in particular noting the need to adapt the design and instruments to fit the culture. CMHS funding has provided tribal communities with a small measure of flexibility in implementing the national evaluation, which has resulted in bringing these communities into the next developmental stage of research capacity as they tailor their evaluation protocols to be more culturally sensitive and begin the process of designing local-level evaluation plans that answer questions posed by their own tribal communities. Services, evaluation, and research with handicapped children and adolescents continue to be desperately needed in Indian Country. The road to evaluation and research in AI/AN communities is clear, the road markers are in place, and the time is now.

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Community-Based Research and American Indians with Disabilities: Learning Together Methods that Work

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Abstract

This paper discusses the importance of culture in social science research and shares knowledge and experience gained through the American Indian Rehabilitation Research and Training Center (AIRRTC). Researchers working through the AIRRTC have found that developing relationships within American Indian communities is critical to the success of a given research effort. The present paper explores this factor, along with several others relevant to community research settings that typically are not discussed formally in rehabilitation graduate training programs. For example, the authors discuss the role of a local or on-site coordinator in assisting university-based researchers to identify American Indians with disabilities who can serve as research participants. Local coordinators can also assist researchers in other aspects of the research, such as interviewing, contributing to a final report, and assisting with public dissemination of results. The paper discusses the importance of developing relationships (some of which may develop into long-term friendships) with key collaborators and gives examples of AIRRTC research to illustrate significant points of our experience. Finally, it addresses the importance of networking by rehabilitation researchers to include international collaborations that focus on indigenous issues and disability.

Just before the turn of our new century, psychologists Segall, Lonner, and Berry (1998) asked, "Can it still be necessary, as we approach the millennium, to advocate that all social scientists . . . take culture seriously into account when attempting to understand human behavior?" (p. 1101). They noted that psychology "has long ignored 'culture' as a source of influence on human behavior and still takes little account of theories or data from other than Euro-American cultures. As national societies become increasingly diverse and international contacts become common, psychologists can no longer assume an acultural or a unicultural stance" (p. 1101).

The same can be said for rehabilitation researchers, specifically, as addressed in this paper, researchers whose studies focus on needs and issues affecting American Indians with disabilities. Rehabilitation research with American Indians who have disabilities is intrinsically linked with culture. Researchers at the American Indian Rehabilitation Research and Training Center (AIRRTC) pay attention to culture because not to pay attention to culture would mean not conducting research in American Indian communities (Marshall,

2001). Culture informs the process of our research, affects our instrumentation, influences our interpretation of results, and contributes to our forms of dissemination.

Since the 1970s, there has been considerable support for the notion that indigenous research should be managed by indigenous people. Indeed, there is a view that nonindigenous researchers have no place in indigenous research (Osborne, 1995). Researchers at the AIRRTC have been both Indian and non-Indian. Regardless of one's position regarding the preferred ethnicity of the researcher, and whether or not she has a disability, we believe in both the value of our work together and the wisdom from the community that informs our work.

Rehabilitation and Research

The AIRRTC, located at Northern Arizona University in Flagstaff, has been in existence since 1983. Funded by the U.S. Department of Education, Office of Special Education and Rehabilitation Services, National Institute on Disability and Rehabilitation Research, it is one of many such organizations in a national network of rehabilitation research and training centers (RTCs). However, only the AIRRTC has as its primary mission the documentation of rehabilitation needs among the indigenous people with disabilities throughout the United States. This documentation is needed to enable state and tribal vocational rehabilitation (VR) programs to develop or improve services that will lead to increased quality of life among American Indians with disabilities. In addition, other rehabilitation agencies and programs, such as independent living services, programs for assistive technology, health services, and rehabilitation education programs, also benefit from AIRRTC research.

Influencing rehabilitation education is indeed an essential outcome of RTC research. Rehabilitation educators, through a core curriculum standardized by a national accreditation body, the Council on Rehabilitation Education (CORE), train those qualified rehabilitation counselors who largely constitute the staff of VR agencies. Bellini and Rumrill (1999) provided an excellent and thorough review of the role of research in rehabilitation counselor education. These authors made a point of acknowledging the need for rehabilitation counselors to apply their knowledge of research in their roles both as practitioners and as active participants in research and program evaluation conducted through and in their agencies' settings. Specifically, Bellini and Rumrill noted that "practitioners can successfully contribute to agency evaluation efforts only to the extent that they appreciate and understand the research that is being conducted" (p. 266).

Our concern? There is no mention by these authors of the role of culture in rehabilitation research. There is no mention of cultural issues being in any way a part of rehabilitation education. Bellini and Rumrill (1999) discussed each of the elements that typically make up an accredited rehabilitation counseling program, including: "foundations of rehabilitation, appraisal process in counseling [assessment], psychosocial aspects of disability, research methods, practicum and internships" (pp. 269-272). In the discussion of curriculum there is no mention of the role of culture. While more than a decade ago CORE noted the need for multicultural issues to be addressed in the rehabilitation curriculum, and this need has been noted by rehabilitation educators (see, e.g., Havranek & Brodwin, 1994; Smart & Smart, 1994), course work involving culture, and certainly course work involving culture and research, does not garner front-and-center attention in rehabilitation education.

Contrast the above "narrow" approach to rehabilitation education with the following notions regarding undergraduate liberal education:

> Liberal education requires that we understand the foundations of knowledge and inquiry about nature, culture and society; that we master core skills of perception, analysis, and expression;

> that we cultivate a respect for truth; *that we recognize the importance of historical and cultural context* [italics added]. Liberal learning is global and pluralistic. It embraces the diversity of ideas and experiences that characterize the social, natural, and intellectual world. To acknowledge such diversity in all its forms is both an intellectual commitment and a social responsibility, for nothing less will equip us to understand our world and to pursue fruitful lives. The ability to think, to learn, and to express oneself both rigorously and creatively, *the capacity to understand ideas and issues in context* [italics added], the commitment to live in society, and the yearning for truth are fundamental features of our humanity. . . . (Association of American Colleges & Universities [AAC&U], 1998).

An additional reason that the cultural context of rehabilitation-related research is so critically important is that rehabilitation educators and the counselors they teach are ethically bound to integrate cultural sensitivity into all aspects of their work, from beginning to end, including research practices. The Commission on Rehabilitation Counselor Certification (CRCC) Code of Professional Ethics for Rehabilitation Counselors, which became effective January 1, 2002, states: "Diversity. Rehabilitation counselors will be sensitive to diversity and research issues with culturally diverse populations and they will seek consultation when appropriate" (Commission on Rehabilitation Counselor Certification, 2002, section H.1 [f], p. 19).

This message, however, needs to come to the profession more emphatically, with more specific direction and strength. It is not enough to have counselors and researchers "being sensitive to" such fundamental aspects of clients' or participants' lives, and only be seeking consultation when or if they think it "appropriate." We must begin to function with research design that is actually *based* in culture, that considers the individual's choices and way of life and their impact on what the counselor or researcher is attempting to accomplish *before* any other factors are addressed (Leung, 2002). We need to stop viewing diversity as a negative factor, listing it along with disability conditions and detrimental barriers. We must begin looking at diversity as a strength, as a defining factor. We must recognize that an individual's ethnicity, language, class, religion, sex, and so on, are cultural "lenses," shaping how we view the world and making each of us unique. Respect for these unique aspects of experience makes an individual stronger and more confident in her or his individual and cultural identity. And respecting these unique aspects of experience, the "culture" of the individual, group, or community, is the only way the researcher can perceive and understand people's life experience, perceptions, and needs with validity. Ethically, cultural factors are integral to the design of research.

Cultural Context: Research in American Indian Communities

The U.S. Surgeon General, in speaking of the need to eliminate disparities in mental health services, stated, "Culture counts" (Daw, 2001, p. 16). Those of us who have worked as clinicians in mental health and with ethnically diverse clients in these and other settings know that "culture counts"—indeed, culture very much matters. Those of us who have conducted research in communities of different cultures know that culture matters. We know that the length of a survey instrument matters. That the content of the questions matters. That the process of obtaining informed consent matters. We know that language matters, that the choice of words, even the choice of synonyms, matters. Regarding the latter point, Brown (1987) noted:

> A writer can create and develop a character through her or his use of dialogue. An upper-class person will draw from a more Latinate word pool and use more subordinate clauses and longer, less volatile speech rhythms. A

> character from the lower classes will use more Anglo-Saxon words, much more colorful speech patterns and shorter, staccato rhythms unless this character is from the American South. In that case, rich and poor alike are more prone to use the rhythm of the King James Version of the Bible. Here again, the poor character will employ more Anglo-Saxon words and will probably be more emotionally direct. . . . Synonyms allow us shadings of class and meaning that can be textured. *They can be felt, not just heard* [italics added]. . . . "If you've fallen through the ice you scream "Help!" not "Aid!" In times of greatest danger or heartbreak even the most aristocratic of people will revert to Anglo-Saxon (p. 13).

So we can say not only that culture "matters" but that culture is actually a "matrix" involving language, for example, as just one aspect of a culture's expression. If research with American Indians who have disabilities fails to take culture into account from the very outset, our understanding of the people and the communities we study will be the less valid for that failure.

Research in the Community

Community-based researchers acquire their knowledge from a variety of disciplines such as anthropology, cross-cultural psychology, and public health. Research processes, as described earlier, are driven by cultural dictates and the context of a given community as well as by theories about research and about working with people. Scholars working with American Indians have much knowledge to share with researchers (Trimble & Medicine, 1993); such cultural information can provide essential context for designing research. Practitioners in various disciplines working with American Indians can also inform researchers regarding both cultural concerns and appropriate research methods (McDonald, 2000, 2001).

For the first author of this paper, "best practices" in research often overlap, such as those derived from theories espoused by feminist researchers (Du Bois, 1983; Gatens-Robinson & Tarvydas, 1992) and inclusive research practices such as the *Consumer Concerns Method* discussed below. Du Bois, for example, initiated her exploration of science and values by stating that "Science is *not* 'value-free'; it cannot be. Science is made by scientists, and both we and our science-making are shaped by our culture" (p. 105). She observed that

> in its conceptions of science and knowing, our society has embraced and reified the values of objective knowledge, expertise, neutrality, separateness, and *opposed* them to the values of subjective knowledge, understanding, art, communion, craft and experience. . . . Objectivity and subjectivity are modes of knowing, analysis, interpretation, understanding. They are not independent of each other, and should not be" (p. 111).

Du Bois went on to suggest that it is the "*synthesis* of subjectivity and objectivity that is the source of intellectual power and responsibility—and truth" (p. 113).

The AIRRTC Experience

AIRRTC community-based research utilizes the principles of Participatory Action Research (PAR; Graves, 1991, 1992; Bruyère, 1993). An important early resource directing our research was the Consumer Concerns Method, a procedure for securing the input of persons with disabilities through working groups that design a given survey instrument, the survey itself, and a public meeting disseminating the results of the survey (Fawcett, Seekins, Wang, Muiu, & Suarez de Balcazar, 1982; Fawcett, Czyzewski, & Lechner, 1986). However, O'Connell (1987) recognized that the method required some adaptation for use with American Indian communities and so proposed to "assess" the adapted model.

Research to assess the proposed model was implemented by AIRRTC researchers Marshall, Johnson, Martin, & Saravanabhavan (1990; see also Marshall, Johnson, Martin, Saravanabhavan, & Bradford, 1992) in the Denver metropolitan area. The model was then replicated by AIRRTC researchers in the Minneapolis-St. Paul metro area (Marshall, Day-Davila, & Mackin, 1992). The Texas Rehabilitation Commission learned of these studies and requested that the AIRRTC carry out this model of research in Dallas-Ft.Worth (Schacht, Hickman, Klibaner, & Jordan, 1993) and then in the Houston Metropolitan area (Schacht, Morris, & Gaseoma, 1993). This AIRRTC version of the model was adapted by other researchers for use with a rural, reservation-based population (McAlees & Pichette, 1993; Pichette, Berven, Menz, & La Fromboise, 1997), and also by AIRRTC researchers for rural reservation needs assessments regarding independent living outcomes (Sanderson, Schacht, Clay, & Maul, 1996).

One important AIRRTC modification of the original Consumer Concerns Method involved using interviews rather than the pencil-and-paper format (involving distribution of the survey by mail to all identified persons with disabilities in the community, with respondents then completing the survey on their own). Recognizing that the written format sent by mail would not be feasible with American Indian populations, because mailing lists of American Indians with disabilities were generally not available and because it was anticipated that the response rate would not be good, O'Connell (1987) proposed to administer the instrument in face-to-face interviews with American Indians with disabilities "in order to increase the level of participation and to insure that the interviewees understand the questions" (p.146). This method seemed the best way to gain both trust and participation in order to obtain valid and reliable information.

The AIRRTC sampling design involved "snowball" sampling (by necessity, as other sampling methods were not practical), beginning with known or identified members of the community who had disabilities. Local media and word-of-mouth were used to recruit participants. In addition, each participant was invited to supply the names of other community members with disabilities who might be interested in participating in the survey.

To conduct the interviews, the AIRRTC recruited and trained American Indians from the community involved in the study, and hired a local American Indian research coordinator to supervise the work of the interviewers. These procedures, consistent with the principles of PAR, were pragmatically designed to produce the best results.

Several types of research questions were addressed. For example, the AIRRTC investigations gathered information on disabling conditions and limitations, Indian people's use of existing services from a variety of agencies, their perceived barriers to needed services, and extensive demographic information. AIRRTC research involved an advisory committee, consisting of both service providers and consumers, throughout the course of the projects. The committee's task was to ensure that the survey questionnaire would produce information that would be truly helpful in improving services for American Indians with disabilities in their service areas, as well as to ensure that the questions were culturally sensitive and appropriate.

The detailed results of AIRRTC community-based research have been presented in publications cited in this paper. We have found that community-specific needs assessments provide important, customized and prioritized information about the needs of American Indians with disabilities. The communities studied have, in turn, used this information in grant proposals (e.g., Lunz, 1998) and for other community development purposes. Another benefit is that in the process of conducting studies, service providers in diverse agencies previously unknown to each other discover common interests and can work together to develop common solutions to

problems documented through AIRRTC research.

There are important methodological issues to be considered in conducting community-based participatory research in American Indian communities. One cannot expect to "jet in" and have everything organized in a few hours. Indian people have often had unpleasant experiences with outsiders asking questions. AIRRTC research experience echoes that of Preloran, Browner, and Lieber (2001) who noted, "Our experiences proved that rapport is as vital to recruitment as it is to qualitative research itself. . . . Our recruitment strategies required relatively extensive and uninhibited access to the potential candidates prior to securing their consent. Candidates who agreed to enroll in the study said they felt we were genuinely concerned about them as individuals and sensitive to the realities of their lives, and they wanted to reciprocate" (pp. 1838-1839).

Preloran et al. (2001) reported that "although in our case recruiters' ethnic backgrounds matched those of participants, this does not mean that our recruitment strategies were successful for this reason alone. Researchers from cultural backgrounds that are different from those of study participants can also develop recruitment strategies that are sensitive to participants' ethnic backgrounds" (p. 1840). For the AIRRTC, "case recruiters" in community-based research most often take the form of "key" collaborators who serve a variety of functions.

The Role of "Key" Collaborators or Community Experts

It is of vital importance to develop collaborative relationships with members of the American Indian communities in which one is doing disability-related community-based research. Researchers who attempt to breach cultural "walls" without the intercession of a community member will be hard pressed to find adequate and appropriate participants for their studies. The AIRRTC experience has been that American Indian key collaborators who are associated with and respected by the community being studied, persons who have expertise in their community, are indeed essential to the research process. Clearly, research results can also be biased by actions taken as a result of key collaborator involvement; thus, in developing relationships within a given community the researcher must bring skills in identifying, approaching, and aligning with a representative variety of key collaborators.

Key collaborators serve as liaisons, facilitators, instructors, guides—and, at times, friends—for the researcher, interfacing with tribal authority should the study be taking place on a reservation, or with community organizations in an urban setting. Because key collaborators, as Indian people, understand and are integrally involved in the research project, they can present the ideas and describe the process to those groups and individuals on a different level than can the non-Indian researcher. They can gain trust and cooperation where the researcher alone might meet only passive resistance or polite incomprehension. They will also educate the researcher regarding attitudes of the participants and expectations—both positive and negative—of the individuals and groups involved. They will instruct the researcher on the need to have frequent and consistent involvement in community activities, which will create a presence of the researcher in the community and increase the comfort level of those involved in the study.

In addition, key collaborators can be extremely valuable in helping the researcher avoid pitfalls which are frequently encountered when working with people from cultures significantly different from one's own. For example, it is imperative that the researcher be, and be perceived as, interested and curious, but not nosy or judgmental. If for any reason the researcher is perceived as being arrogant or self-important, or displays callousness or disrespect toward the individual, group, family, or extended family, that particular interview

will go nowhere, and this problem will quickly be made known to other potential participants. Cooperation must be garnered through polite requests, not officious orders. Confidentiality must be carefully guarded at all times, which can be a challenge considering the closeness of the community and interlinking relationships.

Key collaborators, simply by virtue of being American Indians, will be able to act as buffers for the researcher and significantly smooth the way for valid information sharing. An Indian person is much more likely to place trust in another Indian person because of their shared knowledge, the shared understanding of being Indian people in a non-Indian world, and consequently the fear of being disrespected or looked at with contempt is significantly lessened. A key collaborator can function as a protective shield, softening the impact and anxiety of relating very personal and private information. A key collaborator will help with explanations, bridge language barriers, and facilitate mutual understanding by being able to relate information to the Indian participant in ways only another Indian person would understand—serving as a two-way filter of communication, able to convey the true meaning of the information sought and given.

Finding appropriate participants is not always an easy task in any research project, and frequently there can be problems finding a sample as large as the researcher might hope for. This can be especially true in American Indian communities in general, and if other qualifying issues such as disability are put into the mix the sample narrows even more. Researchers may find that the participant list is small at first, then begins to grow as positive experiences and interactions are reported by word of mouth within the community. The key collaborator will know where to look for participants, and can encourage participants to contact other individuals they know who might be appropriate for the research. Consequently, although the usual methods of identifying research participants might not work, even designs calling for a random sample may eventually prove workable (Marshall, Johnson, Wiggins, & Gotto, 1998).

Integral to the process, then, is finding American Indian key collaborators to work with the researcher and to perform these many and varied activities. While this can be difficult, it is a vital piece in the research process, and must be attended to very early in the process. Frequently, initial contacts within the community can suggest individuals who might be appropriate. Sometimes it is necessary to advertise to find the right person; at other times, word of mouth can suddenly produce exactly the person or persons best suited for the position. However it happens, success in any research project involving American Indians, especially reservation populations, will hinge on the involvement of that key collaborator.

One Example: Eastern Band of Cherokee Indians

Calvin Hill served as an on-site research coordinator for the AIRRTC on the reservation of the Eastern Band of Cherokee Indians. His comments below, prepared for this paper, provide an example of the role of a key collaborator and reveal that valuable outcomes apart from any planned by a program of research can result, even indirectly, from university-community collaborations.

> *The Eastern Band of Cherokee Indians in North Carolina and the Choctaw Tribe in Mississippi participated in a joint qualitative community-based research project sponsored by the AIRRTC, American Indian Family Support Systems and Implications for the Rehabilitation Process (Marshall & Cerveny, 1994; Marshall, Sanders, & Hill, 2001). The study was conducted so service providers could learn how to utilize families in the rehabilitation process. Focus was directed toward the human elements while statistics were ignored. I served as the on-site research*

coordinator on the Qualla Boundary, the reservation of the Eastern Band of Cherokee Indians.

Advantages exist when qualified local Natives are utilized in research projects and are viewed as the determining factor for successful research in Indian Country. Familiarity with the region is a bonus as there are logistical factors to be considered. In the mountains, dense foliage hides driveways, homes, even housing projects from the unobservant. Few signs exist on secondary roads and multiple adjoining roads are unnamed, so caution is recommended to prevent becoming confused and lost. Seven communities are adjacent within our boundary and lines between are crossed often without recognition. Locals take pride in their communities and may resent being mistaken as a member of another community. A person new to the area would show wisdom by having patience and allowing 30 days to familiarize oneself with the region. The service-providing agencies lie scattered throughout the Qualla Boundary. Natives living in the area are familiar with the names of agencies, types of services each provides, and the location of each branch. Advantage lies in knowing hierarchy of agencies and contact persons to seek out for assistance with research.

When making contact with the traditional family, persons with knowledge of Eastern Band of Cherokee Indian customs approach the matriarchal head of family (wife) for permission to interview family. Once permission is granted, a state of goodwill is created between interviewers and family, thus opening doors for communication. A standard courtesy to observe is to sit and make small talk and allow the spokesperson for family to ask the reason for the visit. Many traditional families refuse to relinquish their Native language and retain Cherokee as their primary language. A fluent bilingual person familiar with the three spoken dialects of the Eastern Band of Cherokee Indians is desired to interview a family. One of these, the "Over The Hill Dialect," is supposedly obsolete, though one can occasionally hear it spoken.

It is advantageous for the AIRRTC and other agencies to allow the Native on-site or local research coordinator to perform preliminary home visits and dispel any confusion about pending visits by researchers when approaching the "older generation." Many still harbor deep-seated mistrust of anyone who isn't Native. For the local research coordinator, being visible in a service-providing profession assists in establishing trust and vanquishes fears regarding confidentiality concerns.

Visitations into the communities and homes reveal the struggles entire families endure when providing care to a relative with a disability on a daily basis. A local research coordinator would have knowledge of the plight and history of a given family as contact is made often in the communities. Through use of compassion and humanistic interviewing approaches, light can be brought to problem areas, as well as previously unvoiced concerns and many unresolved issues. Ignorance of available services, false pride, and commitments to provide care alone are at times cited as stumbling blocks that keep families isolated and alienated from needed services.

Active participation in research deemed a turning point in career. *My occupation is to ensure that our elderly, impaired, and the indigent members of our tribe receive the maximum benefits*

to which they are entitled. I am managing and developing the Supplemental Health Insurance Program (SHIP), a service not in place at the time of the AIRRTC research. Working in conjunction with multiple agencies and service providers ensures availability of needed assistance to raise the standard of living for this population. Utilization of holistic approaches serves to uncover areas of need untouched by other providers. Staff at SHIP use humanistic approaches in service delivery and encouragement is given to show compassion and warmth to all served. As a result, our program is considered a model and viewed in a favorable light by the Eastern Band of Cherokee Indians administration and public alike.

Research with Deaf American Indians

While the AIRRTC has had many successes in conducting community-based research, there are challenges ahead—challenges which must be faced but for which there are no easy solutions. One such area of research involves Deaf and hard of hearing American Indians. There is no literature specifically describing the experiences of Deaf American Indians in relation to learning tribal languages, customs, or traditions. However, there appears to be broad inclusion in tribal activities, ranging from passive observation to active participation (James Woodenlegs, personal communication, 1998; see also Kelley, 2001). Of particular interest is the extent of involvement or inclusion of Deaf American Indians in tribal or local school systems and the effectiveness of vocational preparation for them. Virtually all individuals interviewed by one of the authors (HB) were enrolled in state supported schools for the Deaf rather than in tribal or local schools with large Indian populations. This indicates that their formal educational experiences were based in non-Indian settings and locales.

Demographics of the U.S. American Indian and Alaska Native populations indicate that there has been constant and substantial population increase over the past four censuses (U.S. Census Bureau, 2000). Correspondingly, there is likely to be an increase in the number of Deaf and hard of hearing individuals in these populations. The estimated population of 2,450,000 people identified as American Indian and Alaska Native consists of approximately 95,000 individuals who can be classified as Deaf or hard of hearing. This is a conservative calculation utilizing the standard 2% prevalence rate of deafness among general U.S. populations. The figure could be much higher among American Indians due to high rates of middle ear infections, especially in Alaska where indigenous people often live in isolated places with inadequate medical facilities.

Preliminary research supported by both Gallaudet University's Graduate Research Institute and the AIRRTC is now under way to understand better the education and employment experience of Deaf American Indians—specifically, the quality of the transition from school to work provided by their education. The research calls for a series of interviews with Deaf American Indians between the ages of 18 to 34 and is designed to collect information about their school-based academic, vocational, and extracurricular experiences, whether they had graduated or dropped out of school. Participants have been encouraged to share their perceptions of school-based or community-based transition and career development experiences. Post-school outcomes, such as job-seeking skills, employment competence, and upward mobility experiences are also being collected.

Finding Deaf American Indians who fit the criteria for inclusion in this project has proven to be extremely difficult because most of them are scattered throughout the United States and travel is prohibitively costly. The data collected thus far is insufficient to show definite trends or needs among Deaf American

Indians in the area of school-to-work transition programming and planning. However, the number of Deaf and hard of hearing American Indians appears to be sufficiently large to justify ongoing research on a variety of levels. The research would need to include face-to-face interviews to gain input on participants' perceptions of existing services. Demographics could be collected through direct contact with school districts, tribal offices, rehabilitation services, and other related social agencies. This needs to be done for each tribe.

There is a need to obtain information about the employment status of Deaf and hard of hearing American Indians. Questions need to be asked about types of jobs, job settings, income, benefits, insurance, and related employment concerns such as promotions, accessibility, and salaries. There is a need to find out more about educational programs for Deaf and hard of hearing American Indians, and especially about how well they are prepared for careers, post-secondary education, or both. How many Deaf or hard of hearing students attend tribal colleges or universities? What types of services do they receive? Questions need to be asked about family involvement, communication methods, and ways to support family members in providing for the well-being of their Deaf family members. Questions also need to be asked about the level of support family members need for their own well-being (Marshall & Cerveny, 1994).

Learning with Our Neighbors: Rehabilitation Research in a Global Context

Research processes, and measurement in particular, must take into account the values of a given cultural group. Researchers working with American Indians with disabilities can well learn from other indigenous populations (Marshall & Largo, 1999). American Indian peoples, representing less than 1% of the United States population, have been described as "invisible," and certainly Indian people with disabilities are ignored, left out, or not represented in databases and research designed to address disability in general; Indian people with disabilities are not even represented in databases that include other ethnic minorities with disabilities. This is true, for example, on the government website that specifically addresses race, ethnicity, and disability in the United States (U.S. Census Bureau, 2001).

An awareness of other indigenous cultures in the world "adds to the numbers," expanding our knowledge base and exposing rehabilitation researchers to cultural differences that have an impact on research design. For example, Comas-Días, Lykes, & Alarcón (1998) have studied, among others, the indigenous people of Guatemala and stated that "they offer compelling examples of the struggles of indigenous peoples . . . within the context of multiethnic, multiracial societies dominated by lighter skinned descendants of Spaniards, by U.S. regional hegemony, or by both" (p. 778). These researchers noted that "the individualistic, autonomous self driven by personal concerns has been recognized as being [Western] culture-specific rather than universal" and lacked relevance to the Mayan people with whom they worked (p. 783). Specifically, they reported that for the Maya, "to speak of 'who I am' invokes family, community, the animal kingdom, one's traditions and language, and the earth" (p. 783). The need for researchers to acknowledge the collective as a valid, appropriate, and sometimes even primary unit of measure, reference, and significance would be supported by Lang:

> A further question arises concerning the appropriateness and applicability of the western-based notion of empowerment, which presupposes that rights are exercised and that decisions are made in accordance with the preferences and wishes of the individual, to developing countries. Such an individualized notion of empowerment as espoused by the international disability movement runs contrary to accepted social customs and practices that are found in many developing countries. . . . It is

> surely right to question the efficacy of proselytizing western-based individualism, which runs contrary to the collective and communal or familial patters of decision-making . . . . (Lang, 1998, pp. 7-8).

This collectivistic perspective was mirrored in the indigenous people of Mexico, namely Zapotecs, Mixtecas, and Mixes, with whom the first author has worked (Marshall, Gotto, & Bernal Alcántara, 1998; Marshall, Gotto, & Galicia García, 1998; Marshall, Gotto, Pérez Cruz, Flores Rey, & García Juárez, 1996), and clearly calls for research and measurement that recognize and take into account the collective.

The Aboriginal Experience in Research

Researchers in the United States can learn from the experiences of the world's indigenous peoples as they work with governments to define research practices that consider culture as essential context in research. The Australian Aboriginal people have been described as "simultaneously amongst the most researched and the most disadvantaged peoples on Earth" (Scougall, 1997, p. 460). Some hold that research conducted on Australian Aborigines has been, for the most part, insensitive, inadequate, and inappropriate (National Health and Medical Research Council [NHMRC], 1991); has exploited indigenous communities (Victoria University, 2000); and has merely served to advance the "politics of colonial control" (Dodson, 1994, p. 11). For instance, in the early years of colonization, research was preoccupied with "classifying and labeling" Aborigines (Dodson, 1994, p. 3), representing governmental attempts at "management." Research prior to World War II concerned itself primarily with matters of interest to the science of white Australians rather than to the well-being of indigenous communities (National Health and Medical Research Council, 1991).

In 1986, a national conference on "Research Priorities in Aboriginal Health" provided further impetus for developing ethical guidelines to govern the conduct and funding of research into Aboriginal and Torres Strait Islander health issues. Approved in 1991, these guidelines now form the basis of the National Health and Medical Research Council's ethical criteria for Aboriginal and Torres Strait Islander research. These criteria, although focused mostly on medical research, provided clear procedures for researchers and institutional ethics committees in relation to 1) appropriate consultation prior to the initiation of research, 2) community participation in research, and 3) ownership of the data. Researchers were now required to demonstrate that they had sought advice from appropriate local authorities in the community and that the community considered the research to be potentially useful and sensitive. Written consent was required from the community and such consent was to be based on accessible information, personal discussions, and sufficient time for decision-making. Researchers were now obliged to offer appropriate Aboriginal people the opportunity to assist with the research as paid associates. Communities were to be reimbursed for any costs arising from the research. In terms of ownership, communities were given the right to feedback about the research findings, return of raw data, and control over the publication of results in any format. Involvement of Aboriginal research associates in the publication process was encouraged (National Health and Medical Research Council, 1991).

In 1997, the Aboriginal and Torres Strait Islander Commission (ATSIC), a Commonwealth Government Department controlled by an elected Aboriginal Board, released a document outlining the protocols for undertaking research relating to indigenous people (Aboriginal and Torres Strait Islander Commission, 1997). Based on the need for researchers to respect the maintenance and continuance of Aboriginal culture, these protocols called for researchers to reflect the distinct languages, customs, spiritual beliefs, and perspectives of the particular community under study. In particular, the preference in Aboriginal culture for transmitting knowledge

orally should be respected and the topic of the research must not contravene the wishes, customs, or rights of the people.

By 1999, the Australian Research Council (ARC), in collaboration with ATSIC, had produced a report on the ethics of indigenous research (Australian Research Council & Aboriginal and Torres Strait Islander Commission, 1999). The report recommended that all indigenous research should be based on adequate negotiation with and participation of indigenous people throughout the entire life cycle of the project. It also recommended that all projects should include a training component for indigenous people. At the national level, it was recommended that a sound mechanism should be developed to ensure that research priorities are legitimately those of indigenous people.

In an attempt to integrate the conclusions of these investigations, the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) (2000) produced comprehensive guidelines for the conduct of ethical research in indigenous studies. These guidelines, together with the insights offered by experienced researchers and indigenous research organizations, can be synthesized to produce four major principles for successful and ethical research in indigenous communities. These four principles include (1) the need for adequate and appropriate consultation with local communities, (2) sufficient community involvement in and control over the entire research project, (3) demonstrated benefit and sustainable outcomes for the community, and (4) the use of culturally sensitive procedures and methods.

Culturally Sensitive Methods

Perhaps the most subtle but damaging impact of research among indigenous peoples has been the use of culturally insensitive research methods. Western researchers have often been charged with "hearing, but failing to listen" to indigenous people's communications and concerns (Eckermann, Dowd, Martin, Nixon, Gray, & Chong, 1992). Even though many researchers claim to have cultural understanding, this understanding often only skims the surface of the differences between Aboriginal and non-Aboriginal ways (Kendall & Marshall, 2002).

Consequently, the AIATSIS research guidelines (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2000) recommended that researchers new to indigenous communities undertake training in cultural awareness. For example, it is important to acknowledge the fact that indigenous culture in Australia is transmitted primarily by oral storytelling (Scougall, 1997) and data collection should reflect this method (e.g., narrative interviews, observations). As Bostock (cited in Swan & Williams, 1998) commented, Aborigines have all experienced a "cultural disability" caused by ongoing social disadvantage and a history of majority culture attempts to destroy Aboriginal culture and language. The inability of researchers to respond appropriately to expressions of resentment and bitterness about this only increases the mistrust and suspicion that have prevailed between Aboriginal people and European Australians.

Conclusions

The foregoing discussion makes clear the critical importance of culture in social research, especially with indigenous people. Community-based participatory research is one approach which has yielded outcomes valuable to researchers and community members. However, we must also bear in mind ethical concerns in conducting community-based research. For example, it is important to consider not only the overt benefits of research but also the potentially negative impacts of the research process on indigenous communities (Tapp, Kelman, Triandis, Wrightsman, & Coelho, 1974). Lang brought to our attention the problem of "proselytizing western-based individualism" in service delivery. We know that we bring our own cultural perspectives with us to a given research effort (Segall, et al., 1998).

Researchers working without the input of key collaborators or community experts in Indian communities can be sure that their own cultural biases influence their framing of research questions, their choice of methods, their gathering and interpretation of data, their conclusions, and their recommendations. This "error" takes place regardless of the quantitative or qualitative nature of the research. A research project may begin with a quantitative measure of individual happiness, be validated with a majority culture population that values an individualistic worldview, and then be used to assess degree of happiness for an individual indigenous person from a collective society. Because this person's culture was not taken into account, the "objective," quantitative, and "valid" measure, in fact, could *only* produce invalid results.

Focus on an individual community can be essential for local participation in research, for community relevance, and for community action planning. Individual community focus allows researchers to avoid the problem of overgeneralization of results and can bring credibility to the academic researcher's recommendations for problem-solving in relation to rehabilitation needs. Personal relationships with key collaborators can lead to long-term involvements in professional development, community intervention, and new research opportunities. AIRRTC research experience in the community leads us to support the position statement of our colleagues in public health:

> We recognize the power of *equal* partnerships including community-based organizations, academic institutions, and health agencies. . . . We understand that in order for these partnerships to be equal and for interventions to be community-*based*, community members must participate fully in the identification of health issues and the selection, design, implementation and evaluation of programs that address them. (Community-Based Public Health Caucus, 2002, Vision section)

AIRRTC researchers tend not to be bench scientists. While we support and acknowledge the importance of laboratory science in a variety of fields, we have, as Segall et al. (1998) said of themselves,

> . . .long labored in the field, out there among real people in real places and at real times. . . . What is lost in scientific control of the subject matter is, we believe, more than made up by the enhanced validity, especially, the ecological validity, of our findings. . . . We are often confronted by an uneven distribution across ethnic groups of well-being on the one hand and various kinds of distress on the other, and we sense an ethical imperative not to paper over these inequities with dispassionate research reports. (p. 1106)

And thus AIRRTC researchers are called to write passionately of our findings and to act with conviction in the dissemination of our research. We positively affirm that our research processes must be and are influenced by the cultures of American Indians who have disabilities. We are certain that this awareness, and the research procedures it allows us to create in partnership with community members, allows for the "enhanced validity" of our research. We trust that our research can then demonstrate its value and usefulness to the people whom we aspire to serve as researchers and practitioners.

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Learning from and Working with Yup'ik Professionals

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Abstract

This paper describes a participatory action research project carried out by three groups of people: Native Yup'ik Alaskans, the University of Idaho, and the Rural Alaska Community Action Program. The project demonstrates how respectful collaborations among these groups grew into partnerships of progress where Yup'ik educators were able to meet the early childhood education goals of their communities.

The focus of this paper is on a research project carried out by three groups of people: Native Yup'ik Alaskans, the University of Idaho, and the Rural Alaska Community Action Program (RurAL CAP). The purpose is to discuss how these groups collaborated on early childhood education goals in Yup'ik Alaskan communities. A participatory action research process is employed as an overall study design for the project. One key feature of this process is that research is conducted (both formulated and implemented) to benefit the community. A second feature is that researchers conducting the study become involved in the local community (Dickson & Green, 2001).

The paper is organized into several sections. First, background information about Yup'ik culture is presented, followed by information about RurAL CAP and the University of Idaho. Then, sections on the study's methodology and results are covered. The paper concludes with a discussion section.

Culture and Tradition of the Yup'ik People

Yupiugukut: We Are the Real People

> *We call ourselves Yupiit, or "real people." In our language yuk means "person" or human being." Then add pik, meaning "real" or "genuine." We are the real people (Fienup-Riordan, 2000, p. 9).*

The Yup'ik people migrated to the remote area of the Yukon-Kuskokwim Delta on the northwestern shores of North America over 3000 years ago. They settled on the flat delta plain where wildlife and fish were abundant. Fienup-Riordan (2000) described the environment as being as rich in living organisms as the Nile or Tigris-Euphrates River Valleys (p.10). Yup'ik culture developed around the cyclical abundance of plants and animals. Rules for living were taught by word of mouth and thoughtful actions were thought to insure the balance of man and nature. One who showed care toward animals was richly rewarded. The Yup'ik people still believe the environment is responsive to their actions and

attention. At the close of the hunting and gathering seasons, all families share their harvest during traditional ceremonies. The contribution of one who has less is equal to that of one who has much to give. The Yup'ik values of respect, sharing, honoring elders, taking care of others, listening with patience, and respecting shared space are continued and passed on between generations today. A great significance continues to be placed on contribution to the collective good of the group.

Fienup-Riordan (2000) writes, "The Yup'ik people built on their rich resource base, developing a complex cultural tradition prior to the arrival of the first Euro-Americans in the early 1800s. There may have been as many as fifteen thousand people living on the Yukon-Kuskokwim Delta. Following dramatic population declines in the nineteenth and early twentieth centuries, today more than twenty thousand people call the region home—nearly 20% of the total Native population of Alaska. The Yup'ik remain both the most populous Alaska Natives and among the most traditional Native Americans (p.10)."

Since being disturbed by Europeans just over two hundred years ago the Yup'ik way of living life, interdependent with animals, plants and the environment, has suffered greatly at the hands of different cultures. "Although few Russians settled in southwestern Alaska, the larger Russian trade network to the south introduced smallpox into the region, devastating the Native population. Entire villages disappeared, and as much as 60% of the Yup'ik population with whom the Russians were familiar in Bristol Bay and along the Kuskokwim was dead by June 1838" (Fienup-Riordan, 2000, p.23).

This tragedy coincided with the introduction of alcohol to the people. Teresa Pingayak, a Native Alaskan Cup'ik and Head Start program supervisor made this assessment: "The combination of unbearable grief from the great loss of life from small pox and the introduction of alcohol paved the way for current addictive behaviors within our people" (personal communication, February 1998).

After Russia sold Alaska to the United States the Yup'ik people's problems were compounded due to the influence of western Christianity, which demeaned the values and traditions held constant and sacred for thousands of years (Oleska, 1993). In addition, the discovery of oil meant land distribution and contracts that governed land ownership. This altered the hunting-gathering customs of the Yup'ik forever. The repercussion of these changes caused the foundation of the Yup'ik society's social order to erode. The way of life involving subsistence, living arrangements, educational traditions, and a commitment to the collective good was affected and diminished.

While technology, oil, modern education, and alcohol continue to threaten Yup'ik traditions and culture, many positive aspects of the culture are being maintained. The Yup'ik language is preserved in some villages, such as Toksook Bay, where it still flourishes as the first language. Customs are celebrated in traditional festivals and storytelling is still a valued generational occurrence. Many have learned the art of documentation through writing, preserving these traditions and stories. Yup'ik people of today still find their greatest challenge to be saving the old while learning and incorporating enough of the new to survive and flourish. Evidence of this is the accusation that a prominent Yup'ik leader faced. He was accused of being "white." He reciprocated, "Yes, I am part of the western culture; we all are." He then acknowledged the technology that has changed their culture and added, "The challenge is to live in the new and retain the old..." (personal communication, September 1999).

Alaska is not a remote area of the country where the unskilled can survive but a place where unique skills are needed. The ability to walk between two cultural and linguistic worlds is a skill critical to the Yup'ik people's success. One strategy used to achieve the goal

of living in both worlds is local control of education. Each village has a local high school that young people attend rather than being sent to boarding schools in urban centers far away from village life and customs. Yup'ik educators recognize that it is critical to provide English language and technology training programs in order for Yup'ik students to realize their full potential in the western culture. They suggest that many students suffer less from contradictions between Yup'ik values and non-Native cultural values than from a lack of a thorough grounding in either (Hulen, 1991).

It is our belief that education, both Native and western, must begin early, with the youngest members of all communities. Head Start centers staffed by local members of Native descent fulfill this function across the United States. In the Yup'ik villages, Head Start programs are staffed by locals and provide a community approach to learning for the children attending. Head Start parent classes and home visits reflect the traditional values, while Head Start standards based on a nationwide curriculum and system of service delivery help bridge the gap between the old and the new. Head Start also provides employment and on-the-job training with a link to colleges and universities that can result in increased educational opportunities for parents and staff. Head Start personnel participate in in-service education as part of their employment responsibilities and continuing education credits are needed to maintain teaching credentials.

This environment provided this research team an opportunity to practice participatory action research. Village teachers could be involved in research that would benefit their communities, the goal being to promote long-term change in Yup'ik villages. Educators had interests in gaining information and skills that would enhance services to all children and their families. Two content areas of interest were early intervention strategies for at-risk children and creating a team approach for serving persons with special needs. Also important to educators was identifying challenging behaviors due to special needs (for example, fetal alcohol syndrome, developmental delays, environmental and health risk factors). Much was to be accomplished through the research.

Research Partners

From the remoteness of the Yup'ik country came a need for a method of training that would match the particular learning styles and personalities of this culture. Basically, a need existed for a flexible and mobile in-service program. This need, in turn, triggered a partnership between groups of people where respectful collaborations eventually grew into partnerships of progress.

One research partner in the project is the Rural Alaska Community Action Program (RurAL CAP), the umbrella agency for an expansive Head Start program serving over 1,000 children from ages two to five. RurAL CAP's administrative offices are located in Anchorage and many of its service sites are located in the delta plain of western Alaska, home of the Yup'ik people. As mentioned before, the Yup'ik area is extremely remote; there probably is, but it does not seem possible that there could be, a more remote area of our globe. As an illustration, the delta lies about 400 air miles west of Anchorage and once the plane is airborne there are no roads, except in the bustling town of Bethel (equaling in all 16 miles). Bethel provides the only airport in the region, which in turn affords access, services, and commodities to over fifty further-reaching villages.

Another research partner is the University of Idaho, home to an innovative in-service training project entitled Building Effective and Successful Teams (BEST) project. BEST staff members have produced a series of team-directed, self-paced, on-site modules for early childhood professionals. The modules are team-directed in that they are designed for a group (e.g., a Head Start classroom team of educators) not an individual to complete. Further, each team determines what specific content it will apply or adapt to the team's

work setting. The training materials are self-paced and on-site in the sense that each team schedules its own timeline and location to complete the training. These factors make the modules truly individualized educational experiences completed by a community of learners. Data collected from over 90 teams, made up of approximately 700 individual members, indicates a high level of application of newly acquired skills and information to the work setting and an increased sense of teamwork and cooperation among participants (Olson, Murphy, & Olson, 1998; Olson & Murphy, 1999).

BEST project staff members were invited by RurAL CAP to present information about the various modules. The presentation and later discussion focused on how different module contents might benefit local communities, and if the different module contents would be respectful of and consistent with the Yup'ik culture. During the discussion, the Head Start teams expressed the most interest in the BEST module covering teamwork because they needed to streamline their meetings, increase communication among team members, and strengthen their knowledge of cooperative teaming in an educational setting. There was concern, however, that the module content reflected only western European values of time management, goal setting with time lines, communication styles, and meeting norms. The format of the modules also asked participants to jointly and independently complete paper and pencil activities. It was the BEST staff's understanding, from limited previous work with Alaskan groups, that Native people were more comfortable with stories and oral communication and that they were less likely to share information with people who were not well known or who were from "the outside." Another consideration that was discussed was the usefulness of training in team development among a group of individuals whose culture values the contribution to the common good of the group above all other forms of behavior.

Key personnel from RurAL CAP, including Yup'ik members, reviewed the material and felt that the module's content fit with Head Start organizational requirements. In particular, the teams felt they could provide feedback to BEST staff, through journals and assignments, on the cultural relevance of the materials and the need for further partnerships that would benefit the villages.

Based on this feedback, an invitation was extended from RurAl CAP to the BEST project. In turn, BEST staff members extended an invitation to all RurAL CAP Yup'ik Head Start sites to participate in the teaming module process. Out of twenty possible teams, fourteen accepted and agreed to complete the nine-chapter module. Six of the participating teams consisted of culturally homogeneous groups from Yup'ik villages of 400 people or fewer. Teams received support from RurAL CAP and the individual Head Start site managers who granted the time and resources to cover the completion of the module. University credit was also offered for those interested in this option.

In terms of assessing their teamwork skills, teams are given three opportunities. Each of these opportunities involves completing a BEST questionnaire, the Team Profile survey. The profile requires team members to view and critique their team's organizational methods and team meetings. BEST staff members used Yup'ik profile data, plus chapter evaluations and completed assignments, for two purposes: 1) as an opportunity to gather information on the relevance of the teaming materials with Yup'ik people and 2) to compare the remarks of Yup'ik teams with those of Head Start teams from the Pacific Northwest that had completed or were completing the module. Four research questions were developed based on these purposes:

> Research Question One: Will Yup'ik Head Start teams completing the Teaming Module report and maintain gains as measured by the Team Profile?

Research Question Two: Will Team Profile survey scores for the Yup'ik Head Start teams differ from those of the Pacific Northwest Head Start teams?

Research Question Three: Will journal reflections, especially the team's purpose for taking the module, the ground rules they set for their meetings, and the metaphorical statements in color and art, differ between the Yup'ik teams and the Pacific Northwest teams?

Research Question Four: Will Yup'ik teaming results translate into additional training activities that reflect the needs of the involved communities?

Methodology

Subjects

Six teams from Yup'ik villages in rural Alaska and eight teams from rural locations around the Pacific Northwest, similar in size to the Yup'ik teams, participated in the research. The teams included Head Start teachers, aides, bus drivers, and cooks. It took teams about 30 hours to complete the module over a seven-month period. They scheduled their own meeting times and completed assignments and journal entries at their individual paces.

Assessment Tools

Included in the curriculum is a 30-item Team Profile that was completed three times throughout the process. The initial assessment occurred when the first chapter (the teaming module consists of nine chapters) had been completed (pre profile), the second when the entire module was completed (post profile), and the third six months later (follow-up profile). The Team Profile measures team member opinions of the team and how it operates. Ratings were scored on a Likert-type scale ranging from 1 – 5, incorporating items associated with communication, conflict, shared accountability, planning, and effective meeting structures. The results from the Team Profile survey were summarized by consolidating the 30 items into four general categories: communication/conflict, shared accountability, goals/planning and effective meetings; each category contained from 5 to 9 items or questions.

All assignments, journal entries, and the profiles were sent to the BEST project in-service staff. The results of the Team Profiles from individual teams were summarized and the mean calculated for each item on the profile. Strengths that the team reported and areas where there was opportunity for growth were identified and documented and a summary and presentation of strengths and challenges was then returned to each team. At the second meeting (or Chapter 2) of the teaming module, the teams reviewed their Team Profile summary, and used this information to consider what aspects of the module they might perceive as useful for their team.

Training and Support

As teams worked through the module, the BEST staff provided ongoing support through written responses to their assignments or evaluations, as appropriate. These responses included clarifying questions, providing encouragement, and commenting on remarkable details from the materials the teams had submitted. Upon completion of the module each team completed the post Team Profile. A mean score for each item was again computed and compared with the scores from the pre Team Profile. These data comparisons were returned to the team with a summary letter describing changes that had occurred.

At the conclusion of the in-service team training, team members were asked to review future needs for their programs and communities. This was accomplished through an action planning activity where they addressed future interests and goals of the team. They shared their action plan with BEST staff and their administrators. It was anticipated that they would use their teaming skills to enhance their progress towards mutually agreed upon goals.

After a six-month interval, in which no contact occurred between the teams and the BEST in-service team, follow-up letters were mailed asking them to complete the follow-up team profile. Although some team members have moved on to other positions, many are available to complete this third profile.

Results

The research questions stated earlier in this chapter guide this section. The quantitative results from the Team Profile and qualitative data from the journals and other activities were used to compare the experiences of Yup'ik team with those of teams from the Pacific Northwest that were of similar size and that provided Head Start services in similarly rural locations.

Research Question One

The first research area was to determine if the Yup'ik teams reported and maintained gains in teamwork. Mean scores were calculated; the results for the three separate Team Profiles are summarized in Table 1. When considering only pre to post results, Yup'ik teams made gains on 22 out of the 30 items on the Team Profile, with the highest reported scores on the items addressing the issues of "feeling 'safe' on the team," "all members participate," and "all members are to be included in decision making." When a test of means was used to determine significant differences on the pre to post results, nine items showed significance at the .01 level. These nine were primarily associated with staff meetings, including 1) starting on time, 2) having an agenda, 3) utilizing a meeting facilitator, and 4) generating a personal responsibility action plan. Other items showing significant gains related to establishing clear goals, setting timelines for achievement, and accomplishing proposed goals within those timelines. Note that the Yup'ik teams scored highest in the areas of shared accountability and communication on the pre profile and had somewhat lower scores in the areas of goals and planning and meetings. Note also that the post and follow-up surveys show a slight decline in the areas of shared accountability and communication. Items in the goals and planning category increase from pre to post and decline slightly at follow-up. Items associated with the meetings category increase steadily from pre to post and from post to follow-up.

Table 1. Yup'ik Profile Scores by Categories

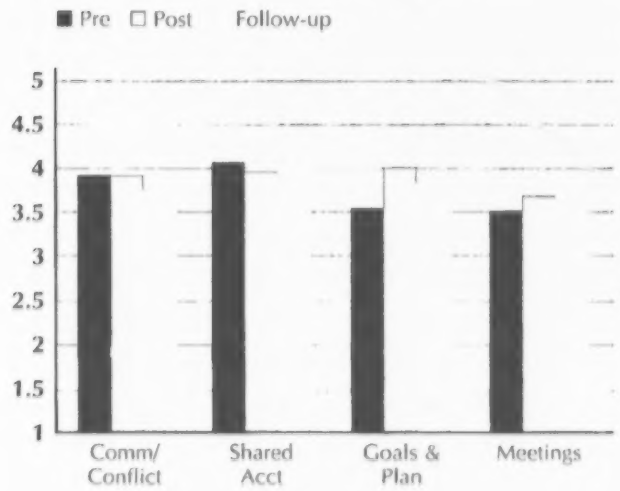
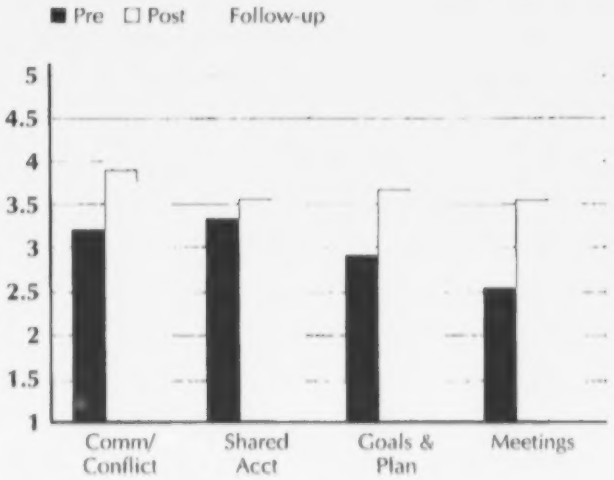


Table 2. PNW Profile Scores by Categories



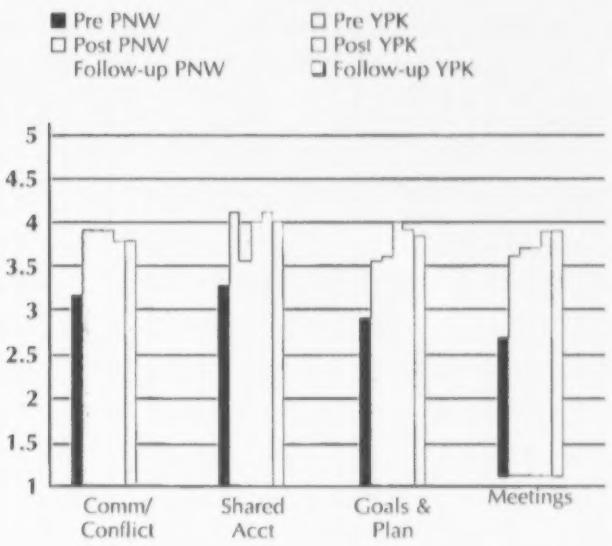
Research Question Two

The second research question examined differences, if any, between Yup'ik teams and rural Pacific Northwest (PNW) teams. Before examining differences, however, PNW team results need to be presented. Table 2 illustrates

the gains of the PNW teams across the four categories assessed by the profile. From pre to post, the PNW teams made progress on all 30 items and 29 of the 30 items showed gains at the .01 level of significance. As can be noted, the PNW teams make stair-step gains in three of the four categories, with only a slight drop in communication and conflict from post to follow-up.

Table 3 provides an overview of how the Yup'ik teams compared to the PNW teams in regard to the four categories. The two groups were very similar on the post and follow-up surveys for the meetings and communication/conflict categories. They were less similar on the pre-surveys over all four categories. Overall, the Yup'ik teams rated themselves higher on the pre profile (27 of the 30 items were significant at the .01 level of significance), with the differences between the two groups converging and becoming more similar at the post profile.

Table 3. PNW & Yup'ik Profile Comparisons by Categories



Research Question Three

Qualitative data were gathered in four areas: journal reflections, metaphorical statements, open-ended questions at the end of the profile, and action planning goals. Research question three asked if journal reflections, especially the team's purpose for taking the module, the ground rules they set for their meetings, and the metaphorical statements in color and art, differed between the Yup'ik and PNW teams. Two Yup'ik teams and three PNW teams submitted journals. Table 4 contains the results.

Figure 1 shows examples from Yup'ik and PNW team members' creations of an art metaphor of the teaming process. The original pictures were in color, and the metaphors and colors used by the two groups were different. The colors of blue, gray, and green seem to represent the landscape of the Alaskan water and winter skies, while the warm colors of yellow and red reflect the rural farm communities of the PNW. The pictorial representations again represent the culture and surroundings of the individual, and appear to be culturally linked. The detail embedded in the Yup'ik drawings may reflect the detail-rich oral stories shared by tribal members, which are also represented in their annual celebrations when masks are created and dances depict the ancient stories of the Yup'ik people. The Yup'ik team members use nature as a medium to express their feelings while PNW teams seem to use geometric figures and metaphors of growth.

The open-ended questions at the conclusion of the post Team Profile asked the team members to reflect on areas they would like to see their team continue to work on. Qualitative review of their comments showed that the Yup'ik teams mentioned communication and action planning and the PNW teams mentioned staying on task and sharing feedback in an honest manner. Both teams mentioned time limits and working together on shared tasks.

Research Question Four

The last question focused on whether the initial teaming module experience with Yup'ik educators would translate into additional

training activities. The teaming module experience allowed BEST staff to build a relationship of trust and open communication with Head Start staff members located in remote villages of Alaska. At the conclusion of the module, the partnership expanded to the development of a home visitors model for the Yup'ik villages. The team members were confident they could implement new ideas and practices concerning early identification of disabilities and developmental delays resulting in families in need obtaining services to address the needs of young children in the communities. They selected the interviewing format for home visiting, screeners for developmental delays, and helped plan the training curriculum they would need over the next three years to be successful as home visitors in their villages. Yup'ik team members brainstormed how to introduce the Ages & Stages Questionnaire (ASQ), an infant screening tool, to their Yup'ik families. They used action planning to assess their training needs and set goals for implementing new skills in their villages.

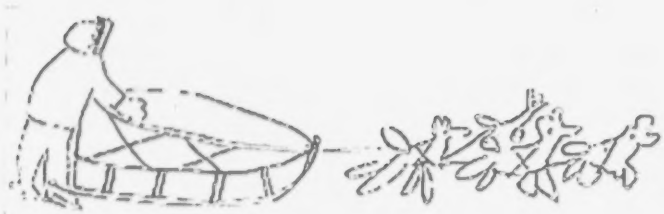
The ASQ, designed for early detection of disabilities and developmental delays in children 0-3 years of age, was a key focus of BEST's next involvement with Yup'ik educators (following the teaming module). Due to the remoteness of the villages, it is difficult for residents to obtain services for their children. If a child needs testing, either a family member has to take the child to Bethel by air or a professional (such as a speech therapist) has to make the trip from Anchorage to Bethel and then fly another 100 miles to the villages. Further, travel in winter months is very weather-dependent. Travelers can be "weathered in or out" for up to 10 days at a time. The ASQ was selected for use in the villages because it can be completed by parents in their own home and can provide parents with information on normal development. In addition, parents reported that use of the instrument gave them new ideas on how to facilitate growth in their child's motor, communication, cognitive, and social development. Thus, the ASQ seemed a potentially useful tool in assisting remote families.

Head Start staff who were trained in and required to complete home visits for all the children attending their schools added the ASQ in order to give structure to their home

Table 4. Yup'ik & PNW Qualitative Comparisons

Journal Entries	Yup'ik Responses	PNW Responses
Purpose for Taking Module	Better communication To work together as a team For university credit	To become an effective team Build on strengths and recognize weaknesses Fulfill mission to serve children and families
Ground rules for meetings	Keep within time frames Stay on the subject/"no storytelling"	Communicate Be on time/stay on task/stay focused Respect each other Listen to each other
Metaphors in color (original drawings were in color)	Blue Green Gray	Yellow Red
Metaphors in Art	Figure 1	Figure 1

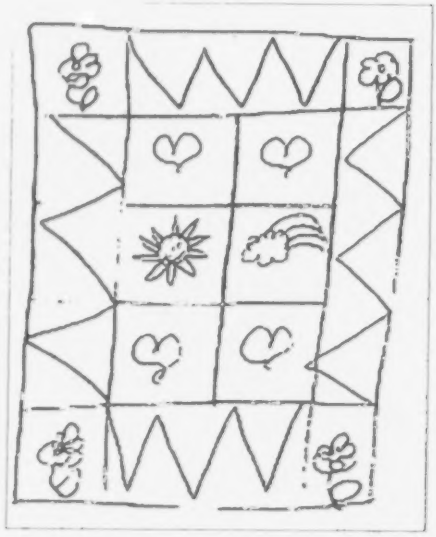
Figure 1. Metaphors in Art (original drawings were in color)



Yup'ik

Yup'ik

Yup'ik



PNW

We are all a piece of the puzzle. We bring together different traits in order to put together a whole picture. (A whole puzzle)

PNW

PNW

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visits and identify early disabilities or developmental delays in the young children.

A great deal of brainstorming was required to set up a model that might work for Yup'ik families. The project design determined that each Head Start home visitor on the team would take six qualifying families that had one or more children aged from birth to three years. It was decided that the home visitor and parent would complete the ASQ together to promote communication and trust. Together they completed activities in the categories of communication skills, gross motor, fine motor, personal-social, and problem solving. The family member provided the material or necessary circumstances for the child to participate in the activity, then after observation documented the child's level of performance on the questionnaire. The home visitor's role was to build the skill and confidence of the parents and to analyze the results of the screening. Each week the teachers discussed their home visits and, as appropriate, the ASQ scores with BEST staff. If the child's performances in any of the activities suggested a delay, the partners brainstormed strategies for meeting the child's needs or, in more complex cases, referred to the proper professional and services for further evaluation.

The teams continued to use the BEST teaming module format for problem solving and brainstorming. It was of utmost importance that team members understood how to develop organizational methods as well as team meetings to address the multifaceted perspectives, circumstances, and challenges that arose in the implementation of the ASQ. In this arena, the teams were able to apply practical experiential teaming experience gained from their work with the BEST teaming module. The partnership continued over the next two years, with BEST staff making weekly contact with the teams and visiting at least once a year for a week debriefing session.

Discussion

Yup'ik teams made and maintained gains in team development as measured by the Team Profile following participation in the teaming module. This outcome clearly dispels the concerns regarding applicability of the teaming material to this culture expressed in the early days of our partnership. Yup'ik team members enthusiastically offered their impressions through chapter assignments and shared their thoughts and dreams through journal entries. They told us their purpose for taking the module was to increase their ability to work as a team and to increase communication. Following participation they said they believed the skills learned would allow them to "be more open to each other." One member stated in the post profile open-ended questions that "it (the module) made me realize some staff members are not as comfortable sharing their differences because they are not understood." Now, after the module, we can "know whose duties need to be done, be more open to one another, and work together as a whole team." Another team indicated the following would occur as a result of their work:

> Teamwork and communication [helped us] make action plans for monthly paperwork for the whole staff to do all year long...not just one person doing that one thing all year long. [We will] use the team, [strategy of] set goals, plan, do, and review.

The Yup'ik teams increased from pre to post in 22 of the 30 items on the Teaming Profile, with nine of these items being significant at the .01 level. Given the initial high scores of these teams, significant gains take on even more importance. The significant scores came primarily in the categories of meetings and goals/planning. Closer examination revealed that all nine items were associated with the themes of effective use of time or goal setting. These are skills typically associated with a more western European approach to service delivery and may reflect the increasing desire among Yup'ik people to live and work successfully "in both worlds." This interest was also reflected in the ground rule of "staying on task with less story telling," which was written by one Yup'ik team member and

repeated several times in the open-ended statements on the post profile. Participants expressed a commitment to work on communication and to use brainstorming when decision making and action planning.

There were apparent differences and similarities between the PNW and Yup'ik teams. First, the PNW teams ranked themselves much lower in the pre profile and then made gains consistent with those of the Yup'ik teams. Of considerable interest was the fact that all teams made their greatest gains in increasing the effectiveness of meetings. The profile items associated with meetings relate to setting agendas, having a facilitator, evaluating effectiveness, and having a "plan for who will do what by when" at the conclusion of the meeting. These skills would appear to be more associated with the western European demand for time management and outcome planning. Yet both Yup'ik and PNW teams made the greatest gains in this category, crossing any imagined cultural lines or assumptions. Both groups recognized a need for efficiency in their meetings when setting ground rules and in the post survey open-ended questions. It appears, then, that effective meetings, including the efficient use of time, are a universal concern for all early childhood teams regardless of ethnic or cultural issues or the homogeneity of the teams. It also appears that shared accountability is a highly valued trait in Head Start teams, regardless of cultural backgrounds.

Not only was the BEST partnership with RurAL CAP and Yup'ik Alaskans productive with the teaming area, but it also expanded into other early childhood areas. The skills of open communication learned during the teaming module helped Head Start personnel share problems and concerns with the BEST staff. A major outcome of the participatory action research and project design process was the enhancement and empowerment of local teachers' confidence to meet the needs of at-risk children and their families through such tools as the ASQ.

In summary, the project resulted in building a supportive network of teachers and families that may facilitate success for the next generations to enhance their skills for being successful in two worlds, that of traditional Yup'ik and the western culture at its door. Our participatory action research project was one of partnership, built on mutual respect and cooperation, that celebrated the strong values and cultural norms of the Yup'ik people and blended the western European tools of early identification of young children at risk for special needs. Through teamwork the partners were highly motivated to perform together the *act* of teamwork and all that it represents.

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Part III
Cross-Cutting Critiques and Discussions

Focus on Research Methods

Spero M. Manson, Ph.D.

I've organized my remarks into two parts. First, I have a series of general reactions to each of the individual papers, which I'll take in the order of their presentation. Second, in synthesizing the lessons learned that you've shared in your respective contributions and considering them in the context of my own experiences, I have noted a variety of challenges and opportunities that are reflected in this work. I'll attempt to summarize them succinctly, as a platform for further discussion. By no means is this meant to be an exhaustive set of comments; rather, I've chosen to highlight a few points and to seek clarification on others.

Beginning with *A Brief History of and Future Considerations for Research in American Indian and Alaska Native Communities*—it's a really nice piece, Jamie. It provides the general historical context that any reader—investigator, sponsor, or consumer—in this particular area needs as the basis for understanding the challenges before us and the backdrop to those challenges.

Early on in your paper, Jamie, you note the importance of translating the results from our work as investigators, or from the scientific research process, into terms that are meaningful at the local level, to the key stakeholders (to borrow Walter's term). This is critically important for several reasons. One is that most of us, based upon the nature of our training, are not adequately prepared to speak in terms that are easily and appropriately consumed by this set of constituents. This poses a major problem for us; I know that it does, in my experience. In the context of tribal review, we prepare scientific manuscripts for which we're seeking the tribe's comments; we also provide community summaries of no more than two pages double-spaced. Nothing drives home the challenge in this translation process more than something as mundane as using the Microsoft Word grammar-level function to figure out the grammar level we've used and the language complexity we're employing. We always exceed the 12th grade level in the first try, and work very hard to simplify it to 8th and 9th grade level. I don't say this pejoratively, implying that our constituents are simple or that their language abilities are limited. The challenge is to render it understandable to most people! I use my parents as the model, because my parents understand both the content and the import of this work. If I can explain it to them, then I'm likely to reach most audiences. This is no easy task; it's one we're not typically trained to do, but it is critically important.

Jamie, the other issue that you've introduced to us—and I'll return to it in my general remarks—is the tension that's at work here. One of the other papers talked about it in terms of the subjective-objective relationship, that we as investigators working in this particular field find ourselves asking, "Where does science end and advocacy begin?" Jamie, you talk about the importance of translating the results of this kind of work into appropriate and meaningful local applications. I agree entirely with you. But I also submit that our training does not equip us to undertake this particular set of tasks.

So how do we go about doing this? Gatherings such as this are an important part of the process. They establish role models. Virtually all of us do this kind of translation. But we have to be able to demonstrate it for our younger colleagues, to illustrate how it's appropriately done. We have to be able to share with them the angst, the trials, and the rewards that accompany this struggle. So this is a particularly important message that you conveyed, Jamie.

As you reviewed the historical backdrop, although his name doesn't appear, his voice

certainly does: Vine Deloria. All of us need to remember Vine Deloria's important work from the early '60s through *Red Earth, White Lies* in 1995, in which he talks about the way local knowledge in our respective Native communities has been judged inferior to the assumed eminence of western science. This is one of your messages: colonization takes a variety of different forms and its effects last many decades.

Jamie, as well, the last portion of this particular manuscript talks about best practices. You provide the readership a very nice overview in regard to the different types of research ethics codes that are emerging in Indian Country, and that are even now finding their way into such taxonomies as the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2000). As a psychologist, you are particularly interested in the latter; it's probably one of the reasons you chose it as an example. But this example illustrates the ways in which some doors are opening even in the most conservative institutions—psychiatry among them. And, Jamie, I encourage you to review *Culture, Medicine and Psychiatry*, beginning with Candace Fleming's article (1996) that helped establish the case studies series in this publication. Three of us have published case studies in this forum, all involving American Indians, using the DSM-IV diagnostic formulation for cultural outline. Candace, Terry O'Nell, and I employed American Indian cases to illustrate how this kind of a cultural formulation moves us well beyond the typical gains of business as usual.

So, a very nice piece. Thank you.

Regarding *Research in Indian Country: Challenges and Changes*, Walter, always a delight to read your work. It's very important that you have called our attention to these three roles—sponsors, consumers, and stakeholders—and critically important for us, as scientists working through such partnerships, to translate the outcomes of these efforts into meaningful terms across all three categories. This tripartite distinction is really at the heart of what may be our first step: a critical analysis of the ways in which these kinds of relationships should unfold and what kind of work we can best apply ourselves to.

Walter, you made a very nice point in regard to the role and responsibility of federal agencies' sponsorship of research in Indian Country. We really do owe a great deal to the Clinton Administration with respect to its support of and advocacy for government-government relationships and consultations. We're beginning to see this come to fruition in various agencies, but not as aggressively nor as comprehensively as such consultation should be. The extent to which this is seriously addressed will take us much further in terms of these sponsors understanding the kinds of issues that are before us. Let me give an example. One of the new, major initiatives that the National Institutes of Health (NIH) is required to address has to do with public access to data generated by its grants. Now, this poses a very particular set of concerns that are thorny for us working in Indian Country, as we consider the full ramifications of such demands. This requirement poses often competing demands when we work with our tribal and community-based partners.

Walter, you hit the nail on the head in your manuscript when you wrote about the major scientific challenges that face us with respect to sampling: the "denominator problem," whether it be with the census or with the community-based work that we must do to capture the data needed to address broader issues. In our work, epidemiologically, etc., sampling is an enormous challenge for us. And it brings us back to an issue that I'll return to in my more general remarks: the tension between generalizability and local specificity of research findings, which have different kinds of constituents and different lessons attached to them.

Walter, you also talk about there being an increasing number of institutional review boards (IRBs) in Indian and Native

communities. Through a fairly systematic survey I'm aware, right now, of nine formally chartered IRBs in Indian Country, three or four of which are very active. However, it's not my sense that at present many IRBs are tribally operated and administered. For the most part, many tribes look to the Indian Health Service and its area offices to serve that function for them. I'll return to this point. It's a big issue for our communities, for us, and for sponsors. How does one promote, support, and encourage the development of tribal-level IRBs? There are a number of challenges for everybody; not the least is how they'll be financially supported, which is not clear—and often not even the case. Our investigative team has discovered several solutions, but until our sponsors recognize that part of their responsibility is to help finance such review structures, we will be frustrated by the speed with which we see tribal IRBs working in our respective communities.

Walter, you raise several interesting tensions having to do with the issue of confidentiality. I'm always amazed at the extent to which non-Native colleagues are surprised by the emphasis on community confidentiality in reporting research findings. They understand and respect the importance of confidentiality regarding the individual, but are puzzled by why many communities would want this respect extended to their entire communities. I refer them to an article published some years ago that led to the establishment of the Navajo Nation Health Research Review Board. For that article, CDC investigators, in collaboration with the Navajo Health Authority, had agreed to present their manuscript on the epidemiology of the Hanta Virus during the initial peak of concern. The Navajo Nation approved it, asking that the 20 communities not be identified but named in a way that wouldn't diminish the scientific basis of the findings, thereby avoiding local stigmatization. The CDC agreed—but when the article appeared the Navajo communities *were* named, abrogating their agreement. Early in that investigation, a newspaper in Denver carried a front page headline, a half-page picture of a hogan, and a caption that spoke of the "Navajo flu" and dirty living conditions, implying that traditional lifestyle contributed to the risk of that particular disease. This was right on the heels of that particular publication by the CDC—underscoring the stigma and the rightful concerns of the Navajo Nation.

Walter, you talk about how the quality of the data collected is often improved by enhanced communication, better rapport between researchers and study participants. Then you qualify this as you talk about the costs and benefits of trying to accomplish this match between the people who collect data and the people who give it as a gift. It's a very important point. For the most part, those who are inexperienced or less experienced with these issues assume that it's a ready-made solution: if a Native person is part of your data collection team, you will be immediately catapulted over such problems. You provided several excellent examples to the contrary, illustrating how it's not necessarily the solution, the panacea, one might assume.

In a recently completed two-stage epidemiological study of alcohol use and dependence in a Northern Plains community, the first stage involved administering sensitive questions to community members. The reported rates of alcohol abuse and dependence were quite low in the data generated by that phase. But in the second phase, a clinical reinterview of a large subsample of the same study participants, we observed rates of alcohol abuse and dependence several times greater than estimates based on the first stage. In debriefing our team we found, in fact, that we had inadvertently staffed one of our field offices largely with recovering alcoholics—so the community members whom they interviewed in the first stage felt less disposed to disclose their true personal histories of alcoholism. This reminds us that there are trade-offs. The message you've conveyed is that we need to be critically thoughtful about the advantages and disadvantages in hiring Native persons

from a given community to assist with data collection in that community.

Walter, you also talk about the issue of individual informed consent. There are two excellent examples of the challenges that we face in Native communities as we approach this issue. Joseph Carrese, an associate editor of the *Journal of General Internal Medicine* at Johns Hopkins, published an article about six years ago (Carrese, 1995) that demonstrates so powerfully the challenges that we face in appropriately informing study participants, and the role that culture plays in this regard. The example he gives is that among the Navajo it is believed that giving voice to bad things, negative things, increases the probability that those things will occur.

What do we do in an informed consent form? We present a long litany of possible risks. We characterize all the possible adverse events that might occur through participation in this study—hence violating at the very outset the Navajo view that giving voice to such things increases the likelihood of their occurrence. How do we address such issues in the informed consent process? And that's beyond all of the other potential barriers, such as language comprehension, etc.

There's another issue with respect to informed consent that we experienced (Norton & Manson, 1996); it has to do with who is appropriate to give informed consent. In this particular study we worked in five different tribal culture areas; one was in the southwest, involving several pueblos. In visiting the tribal council, we reviewed the research protocol, indicating that individual informed consent would be required. The council refused. They said, in effect, "We as the Tribal Council are responsible for providing consent for all of our tribal members." It was an expression of the manner in which that tribe is organized socially, in terms of its collective responsibility for members.

This proved to be an extremely thorny issue with our institutional review board (IRB) here at the University of Colorado Health Sciences Center. Ultimately, a compromise was reached. But this example underscores how even the notions that guide the informed consent process and that are embodied within our IRB processes reflect particular cultural assumptions about responsibility, authority, and individuality. Walter, those strike me as two useful examples that you might use to emphasize this point.

Regarding *Cultural Competence Approaches to Evaluation in Tribal Communities*, Paulette, delightful; a pleasure to read your paper. You've nicely captured an issue that Catherine and her colleagues note in their manuscript as well: the importance of attending to the local construction of the phenomena, the experiences, that our research seeks to understand, describe, and explain. Your example, Paulette, relates to the concept of disability. You mention it in the context of the Global Assessment of Functioning (GAF) (American Psychiatric Association, 2000) and of various tribal grantees' attempts to operationalize this construct in locally meaningful terms. This is a key struggle for us, and for sponsors as well, to recognize. This is an instructive lesson, Paulette, and there are other examples in the literature which you might consider referencing here. Especially when coupled with the manuscript by Catherine and her colleagues, your paper exhorts us to be more reflective, more systematic, in our search for locally meaningful constructs of this nature.

A current example, not reflected in these manuscripts but certainly anticipated by them, is "spirituality." Paulette, your manuscript touches a little bit on spirituality; our Circles of Care initiative is centrally concerned with this concept. How do we measure spirituality? How do we build it in to our evaluation strategies? Into our research approaches? We were driven to do this in our work. I was reluctant, as a scientist, because it seemed to threaten polluting the sacred with the profane. By that I mean, why should we assume that western scientific methods lend themselves to measuring such a sensitive construct as

spirituality—or that it would even be appropriate to do so? Frankly, it was our Navajo colleagues who challenged me on this. They said, "We want to. To the extent that it can be measured, we believe it will prove critically important to understanding risk and protection among our people, as well as broadening the theories and models available to us from the general literature." So that is a lovely point.

The converse, which you also talk about, is the frequent observation that "wraparound services" is a familiar notion in Indian communities, one we've adopted for a long time. It's probably no accident that John VanDenBerg (VanDenBerg & Minton, 1987), one of the earliest advocates of wraparound services, did his first work in Alaska. Much of his work in the Alaska Youth Initiative involved Native villages, wherein life emulates many of the basic tenets of the wraparound model. So another important observation is not just that it's important to adapt these kinds of things for application in Native communities, but that there are lessons to be learned from doing so, and that the greater world of science can benefit from careful attention to these matters.

Now I'm going to take you to task a little bit. I can do so, being a little more privy than most to some of the tensions that emerged with respect to the Systems of Care initiative through my participation at meetings that brought the Indian and Native grantees together with ORC Macro to debate the adequacy and the felt imposition of the national evaluation model on the formers' communities. You persuasively characterized the way in which the Indian and Native grantees challenged ORC Macro to develop new constructs or to adapt the national evaluation plan's existing constructs. But what's lost in your discussion, Paulette, and is important for the audience to share in, is the tensions that were at issue, not just that they were resolved.

That will return us later to more general remarks regarding tension between the general and the specific. Meanwhile, though, it would be helpful if you elaborated and shared the tensions and the demands on Macro. They had a responsibility to develop a national evaluation plan, and did so in good spirit and with good intention based upon a particular set of scientific tenets about the notion of comparability, reinforced by a scientific advisory board—a board that I happen to be on. Yet, at the same time, Macro was pressured by Congress and by the Center for Mental Health Services (CMHS) to produce evidence as to the effectiveness of this particular initiative that cuts across the grantees. Grantees sought to be responsive to these demands, recognizing their contractual obligations. But, at the same time, they suffered from the imposition of an external view of process and outcomes. At the same time, the grantees did not understand the organizational constraints on Macro that limit its ability to respond. So, it would be helpful to the audience if you bring to the fore a bit more the human fabric that underlies some of these tensions. One of the lessons here is demonstrating or chronicling these lessons, enabling other agencies, other sponsors, and other grantees to acquire a better sense of what issues to anticipate and the paths to their solution. Of course, they're not yet solved at this point, but well on their way to appropriate solutions. A lot of this is, as you know, process. This is the piece missing here: conveying to the audience the process by which these important milestones were achieved.

Okay, Paulette, now I'll let you off the hook; it's a nice piece of work.

Catherine, I was very pleased to see that *Community-Based Research and American Indians with Disabilities: Learning Together Methods that Work,* more than any other paper here, takes head-on the issue that "culture counts"—a phrase borrowed from the *APA Monitor* summary (Daw, 2001), as cited in your paper. In fact, there's a whole chapter on culture that appears in the 2001 supplement to the Surgeon General's 1999 report on the *Mental Health of the Nation* (U.S. Department

of Health and Human Services, 1999). It was a major battle to get the various agencies to actually adopt this language—that "culture counts." Your paper, more than any other here, underscores the issue, and reminds the audience that this is not just a matter of American Indians or Alaska Natives vis-à-vis some broader societal group, but a matter of culture, involving process, dynamic, meaning. So this is critically important.

This manuscript is also the only one that talks about urban issues, which are vitally important. You speak about the strengths and weaknesses of your community assessment approach, which was pencil-and-paper originally, and your subsequent adaptation of the method. You did this in Denver and Texas, if memory serves, and subsequently in Minneapolis. It's a nice example of how to carry forward a set of methods, adapting to the voices in our respective communities.

In this portion of your work you're drawing upon your own experience, but there's another example that may be useful to reference, having been used both in reservations as well as urban settings: the Community Readiness Model developed by Colorado State University (Jumper-Thurman, Beauvais, Plested, Edwards, Helm, & Oetting, 2001). It serves a similar kind of purpose. We all would benefit by looking more closely at both kinds of approaches. Each represents thoughtful, systematic ways of giving voice to the stakeholders, in Walter's terms, who are represented in these communities.

This manuscript goes to great lengths about the importance of key collaborators. I fully agree with the underscoring of the importance of the key collaborators. But let me note that the people who choose to collaborate with us are not devoid of their own agendas. They have their particular views. They have their particular priorities. It's important for us to be critical, analytic, about who chooses to collaborate, what may be at stake for them, and what they see as the issues, benefits, and costs. Collaboration is critical. Identifying key stakeholders to participate in these partnerships is critical. But another important part of the process is to retain a self-reflexive perspective, to understand who has agreed to collaborate with us and whom we have collaborated with. We all know that in working in our communities, joining with one person often precludes our ability to work with others. And what does that have to say about the particular views to which we are privy? About the tasks we have chosen to undertake? About the outcomes desired and thought possible?

Learning from and Working with Yup'ik Professionals is a lovely work. As you noted, Jennifer, it is different from the others in terms of initial orientation and focus. But it's an extremely valuable contribution. You've taken the Ages and Stages modules and demonstrated the use of certain organizational techniques to build teams with certain kinds of outcomes. You've taken us more deeply into the processes often at work at the more abstract level. You've done it within a systematic framework that allows us to examine how those processes unfold in similar or different ways among Yup'ik and non-Native northwest professionals. Although I encourage you to explore this even more deeply, you were able to talk about some of the apparent "disconnect" between the Yup'ik approach and how their cultural values of respectful listening and patience seemed at some points to run counter to the process. In debriefing Yup'ik participants, you asked what they might like to change in a reiteration. They suggested more structured settings that would allow them to comfortably adopt the particular values assumed in the Ages and Stages approach, thereby enabling them to engage in a dialogue, in a narrative, in discussions that would otherwise be more difficult. But this is really more than a case study, Jennifer. Quantitative and qualitative investigative techniques have been integrated and then applied to a process that may be generalizable beyond these particular groups. Let's face it, issues of organizational culture are among the

biggest challenges for us to address as we navigate the various partnerships that emerge in our work.

Now, let me try to characterize for you more broadly what I believe to be the challenges as well as the opportunities that your papers anticipate for us, and that my modest experience suggests to me, as well.

First, the tensions anticipated in my earlier comments. There is a general tension between science and advocacy that we need to address openly. It goes to the heart of the manner in which we're trained and how most people construe the appropriate role of science and scientist. Only recently have sponsors such as NIH begun to talk about the importance of the translation process. They're even talking about "translational science"—about how to systematically translate research findings, whether in the lab or more controlled experimental settings, into meaningful, real-world applications. We're not trained to do this; we're not well equipped to make such translations. These efforts also typically are not funded by our sponsors, so that it falls to us to expend the extra time and energy to accomplish them. The translation process also engenders a fair bit of discomfort for us; we're extending ourselves into areas that are less familiar than other areas. But this is an important undertaking; our communities demand this of us, that we engage in advocacy and in this translation process.

There are other tensions mentioned earlier, and that Walter touched upon in his discussion of sampling: generalizability and local specificity. Paulette, it surfaces among the evaluation issues that you and Brigitte face with respect to Macro. How does one deal, scientifically, with the notion of comparability in a way that is locally meaningful and that speaks to the integrity of the initiative you're a part of? How do we generate outcomes or results that can speak to the general effort, but that are at the same time locally meaningful? Not easy tasks.

Yet a different tension springs from the mandate to compare—namely, the assumption that uniformity somehow brings with it, as a natural consequence, comparability. Not true—but it's part of the challenge that we face as scientists, in educating our fellow colleagues as well as in working in our respective communities, to find points of compromise.

There are other tensions as well, between academic freedom and tribal sovereignty. Working recently with a colleague, I became distressed at how much more work we have yet to do and progress yet to accomplish. The individual in question had conducted work in a community with which we had agreed to present all presentations and publications for prior review and approval. Despite being Native, despite being aware of our agreement, this colleague, wishing to present a paper at a forthcoming conference, but absent tribal approval, asserted the primacy of academic freedom over tribal sovereignty, couching the issue in terms of censorship. There may be some merit to her argument, rooted in the history of how we've been trained to do science and the expectations of the institutions in which we work. But it was appalling to me that this argument issued from a young, Native colleague, underscoring the work still before us.

Shifting from these tensions to other challenges, I mentioned earlier the issue of supporting—not just in principle, but financially—local tribal review processes. This is not a straightforward matter. Our experience over the last four years of working directly with tribal IRBs reveals an enormous amount of variability among them in terms of their organization, the speed at which they move, the kinds of information they request, their decision-making processes. And not minimal by any means is the issue of how that entire endeavor is financed at the local level. If we're serious as sponsors, consumers, and stakeholders about promoting tribal review, we have to become serious about funding it.

Discussions with the National Institute of Mental Health (NIMH) in recent months have yielded their agreement to include in grants subcontracts to our tribal partners to fund this process. Yet, several other institutes have rejected this approach out of hand. There is considerable variability among the institutes at NIH, but this foothold gives me greater optimism for addressing this important need.

I've also suggested to several of these tribal review boards, each dramatically underfunded, that they charge for the review process, which also makes it easier to build such costs into research funding mechanisms. In Colorado (and this is true in many other universities), the Colorado Multiple Institutional Review Board charges $1,200 to review applications not submitted by members of our institution. Well, why can't tribal IRBs adopt a similar private enterprise model for those investigators wishing to work in their communities? There are solutions out there. We just have to become more aggressive in seeking them.

One issue that arises as a natural segue with respect to this issue of local review has to do with ownership of data. I confess to being caught in the middle of interesting struggles about the ownership of data. NIH, the sponsor of most of our work, asserts that we, as principal investigators, own the data. My institution has a particular view on that as well. Several of the tribes with which we work also assert that they own the data. So what does ownership mean? Is there multiple ownership of data? Are there different but complementary applications of the data? How does one pursue this notion of multiplicity of ownership? How does one negotiate the respective responsibilities and areas of mutual responsibility?

NIH has instituted a major policy regarding public access to data to ensure that data is shared, that it doesn't just sit in some investigator's computer unused for decades, that the investment the American public has made in sponsoring such work actually sees the light of day. How does one think about meeting the spirit of this intent when working with entities that also claim ownership of the data? And we all have very appropriate concerns about what is subsequently done with data.

Walter, you pointed out that the greatest area of contention right now is in terms of the ethical, social, and legal implications of genetic research, particularly in American Indian and Alaska Native communities. That particularly volatile issue involves commercialization and the subsequent profit that may derive from gene banks, etc. These recent concerns heighten the debate, and tend to polarize views on the research process. How do we navigate these shoals, remaining open to reason and reasonable arguments?

What's the threshold for seeking permission to disseminate findings? Is it simply naming our tribal partners in the products of this dissemination? Paulette, your paper raises interesting challenges for us in this regard. You solicited feedback from the tribal grantees, the Indian grantees, in your paper. What constitutes permission? Did they all send back something formal that you can document as having given their permission to name them in your particular manuscript? Jill, you know our struggle in preparing the *Promising Practices Monograph* for Circles of Care (Burns & Goldman, 1999). What standards should we adhere to? What are realistic expectations, especially in the face of the demands and the lack of resources among our community partners to act on these kinds of requests in some cases? Who represents the community? Is it always the tribal council? Is it the health and human services committee? It's often the case that it's *not clear* who represents the community.

Community-based participatory research requires an enormous amount of time and effort. I'm almost frightened to calculate how much time is spent engaging our community partners, throughout the research process. The tribal review of our manuscripts alone, for

example, adds at least seven to nine months, in most cases, to submission of a manuscript to a journal for review, and if the peer review requires substantive modifications, tribal re-review is necessary—a process that adds at least 12, maybe as much as 18 months of capital investment of time and energy. It presents a major problem for our younger colleagues.

For those of us in the academy, with many younger Native colleagues trying to break through the sometimes not-so-transparent ceiling in terms of successful promotion and tenure in medical schools or colleges of liberal arts and sciences, the currency of success is grantsmanship and publications. The longer it takes, the less likely we are to succeed. There are only 11 American Indians and Alaska Natives who are associate professors or above in medical schools in the entire country. When one looks at the rate of success, one finds that the vast majority never make it from assistant professor to associate professor—and that's in large part because we're Native. We are assigned a disproportionate amount of responsibility for various committees in our respective universities. We're asked to teach more. The kind of work we do takes two to three times longer if we're committed to doing it in the way suggested by these papers and in which we all believe. So there are many challenges before us. One is to ensure that people become educated about such issues, about possible solutions. And it may have to do with modifying routes by which one rises through the academy.

Just two other things to comment on. I've been struck by the experiences of two of the tribes with which we've been working most closely in recent years. Indian Health Service (IHS) area IRBs previously performed the review process on their behalf. Recently, both tribes have rescinded this relationship, concerned about tribal sovereignty and delegation of that decision-making process to the IHS. This action has raised some interesting dilemmas for us as we've moved forward in the research. One of the dilemmas has to do with contracting relationships with the IHS where IHS contracts with a given tribe for the tribe to provide some of their own health services. The IHS asserts—Dr. Bill Freeman, former Director of Research for the IHS, was an eloquent spokesman in this regard—that if a particular facility or group of resources, be they people or records, are funded through contract dollars, the IHS IRB has jurisdiction. However, if the research at issue involves a facility or resources funded through a Public Law 93-638 contract (Indian Self-Determination and Education Assistance Act, 1975), many tribes believe that it's their responsibility, and falls under their jurisdiction, not the IHS's. So there's a major conflict. Compacting, where tribes choose to manage all health service resources, presents an entirely different set of circumstances. The Indian Health Service readily recognizes that the tribes have direct, immediate, and primary responsibility for reviewing research that involves compacted personnel and facilities.

The point I'd like to end on, and the biggest issue facing us, is this: *Our discussion is not new*. Beginning in the late '60s, many, many conferences and symposia have been organized around the very same issues and concerns voiced here today. Travel forward in time to the early '80s—one sees a new series of conferences, symposia, and initiatives on exactly this same topic. Here we are again, 12 to 15 years later. What do we need to do to carry forward the momentum that these efforts began? To weave these conversations together, establishing a sense of continuity and ongoing immediacy to the discussion? What does it take to move this dialogue further along than we've been able to do on past occasions? I don't have an answer, but it needs to be one of the critical questions we must pose to ourselves if we are to have greater impact than history suggests we otherwise are likely to have.

These are my thoughts, then. Thank you very much for the opportunity to read your respective manuscripts. I look forward to future discussion.

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Ms. Holly Echo-Hawk: Thank you very much, Spero, for your very deep and thought-provoking comments. I think now we can just open it up to some dialogue and questions, to take advantage of Spero's time with us

Dr. Philip Olson: Spero, do you have any insight into what happened to the 1960-1980 start in these kinds of discussions that didn't make it, from your point of view?

Dr. Spero Manson: I think there are these three things: First and most obvious, there wasn't a critical mass like this. I was brand new in 1976, when I started out in the field, and you could count on your hands the number of people who were already there. Of course, many of us looked to Carolyn Attneave for a long time as one of the major leaders, but Dean Edison was also there, and there were some other voices—but they were easily ignored, for the most part, by the majority of people in respected disciplines and in the areas of sponsorship. I think we're approaching a critical mass of people, Native as well as non-Native, who take these issues seriously, are building them into our work, and trying to model it for others.

The second difference, I think, is that sponsors are now echoing the importance of community-based participatory research. It assumed all different labels in past iterations, but we're pressing and hearing sponsors respond more constructively about how to build the infrastructure to make this happen.

And I think the third thing is related to self-determination and tribal sovereignty. We do now have, for the very first time, tribal IRBs [institutional review boards], variable as they may be in their success—but they're there as examples, and other tribes can now look to them. And I think the Albuquerque Indian Law Center Tribal Codes from 10-12 years ago really never took off because there wasn't this kind of infrastructure that tribes could marry it to, and now I think we're beginning to see that.

So those are at least three reasons, I think, that there's good promise for this effort continuing.

Dr. Turner Goins: Spero, you brought up earlier the tension between advocacy and science. As a junior researcher I was always taught that they are two different things and to be careful not to present yourself as an advocate, particularly in the eyes of a sponsor such as NIH. Can you talk about that a little bit more?

Dr. Spero Manson: I think you've just said it as well as I could—that we were taught that the two were very different and that they should remain mutually exclusive. We have to go back to the long-standing characterization or at least separation of basic from applied sciences. Walter, you used the word "applied research" earlier; I think that characterizes most of us, and we're proud of the fact that it characterizes us. But in the majority of our fields applied research has long had a sense of being somehow less rigorous and not the preeminent model of how science should be done. It's messy and dirty. That's a lot of what we see at work in these debates and why we're often marginalized in our respective disciplines, to the extent that we do seek to translate our work into locally meaningful terms.

We can use language to reframe what we do. Our communities understand it as advocacy. What are some examples? We worked with the Navajo Nation on the American Indian Vietnam Veterans Project, conducting research on the role that traditional healing played in the reduction of risk or the increase of protection of Navajo Vietnam veterans from the negative outcomes of combat. They were adamant that they needed not just the findings but a partner to go forward with them to

Congress to help translate that science, which was good science, into terms that Congressional delegates understand. We're not equipped. We're not expected to do those kinds of things. But it's my experience that our tribal partners are looking more and more for that dimension to the partnerships that we seek with them.

I think one can do that. I think one ought to do that, and I think one can do it effectively—but it takes good role models. It takes experience and getting your nose bloodied a few times to figure out how to do it well. Our communities are expecting that of us and more power to them. They should.

Dr. Robert Schacht: I'm wondering if part of the answer might be in Jamie's paper. She talks about the influence of context on how we ask questions, and the debate that has come in connection with postmodernism, that frames the questions "What is science?" and "How do we really know what we know?" in a way that was not true or not as available in the '60s and '80s. We've gotten far enough down that road that maybe we're at a point where science no longer rules the debate the same way that it did, and that cultural issues with respect to how we ask questions have opened things up in a way that they weren't before. I wondered if you might comment about that possibility.

Dr. Spero Manson: My sense of the extent to which we're successful in that regard rests on the degree to which we're successful in demonstrating—in other colleagues' own terms—what the benefits are. For example, if you take Al Bandura's social learning theory and 1) demonstrate, in its application to a variety of different settings with American Indian and Alaska Natives, the limits of that theory as it stands; 2) demonstrate, through some of the very creative methodologies that are beginning to emerge—represented in a number of these papers—how we can better articulate local cultural experience in ways that will lend themselves to being operationalized; and 3) examine, through these scientific methods, the contribution they make to enhancing and extending theories like social learning theory or health service utilization, etc., these are the grounds on which we can make the most immediate success and greatest progress.

The gnawing thing is that to be successful in the short-term you have to do it in their terms. That grates on me. There are colleagues who say, "I'm not going to take up that challenge. I'd rather work from the outside and snipe." I'm an internal revolutionary. I'd rather work from within and try to extend.

Jamie, for the work on DSM-IV [Diagnostic and Statistical Manual of Mental Disorders], I was part of the steering committee for NIMH [National Institute of Mental Health]. There were eight of us who took as a major challenge the formulation of the cultural guidelines, and as a consequence the difference between DSM-IIIR and DSM-IV is that we see culture there throughout the DSM. We're now seeing, through residency and accreditation bodies, a growing emphasis on respectful and appropriate attention to culture in the diagnostic and assessment process.

That's the route that I've chosen to take. It illustrates that, even if you accept the DSM on its own terms, you can work within that framework and develop knowledge based upon the kinds of things that we would count as important; you can make a difference. It's not the only way, but it's one route available to us, and to the extent we're willing to take up similar kinds of arms, if you will, we can successfully do this battle.

Dr. Walter Hillabrant: I do want to say just one thing, going along with your theme about the dilemma of advocacy versus research. A lot of times it gets expressed in program evaluations. One of the things that I learned—and it's sort of like getting your nose bloody—is one of the things I think my mother told me: "When in doubt tell the truth"—because no matter what you do you're going to gore somebody's ox and somebody is going to be pissed at you, so you might as well lay it out as it seems to be.

The dilemma that we get in advocacy vs. science is, who are the people who ally themselves with us? They're not necessarily representative of all the stakeholders in the community. And to the degree you're involved with one individual or one subset, you probably aren't with another.

Therefore, with respect to advocacy [as an outcome of research or evaluation], my point is that it's not always advocacy for the here-and-now or even with the majority of the members of a community, and if you take the seven generation perspective and so forth, then who are you to decide? We all have those dilemmas and this conversation is really helping.

Dr. Catherine Marshall: The piece that Walter was talking about—our work being biased by those who choose to collaborate with us or who are key informants: Of course, we've all been taught about what happened when research subjects were Psych 101 students, that some of those "experimental designs" were, in fact, influenced by who the subjects were. So now we need to talk about and make room for the "limitations" of our study as being biased by the key informants. I've had conversations over coffee about that, but I don't think I've written about it. An example here with us is Mr. Calvin Hill, from Cherokee. I can clearly say that in a study we did, interviewing 20 families, the findings of that study (i.e., the needs and issues of those people with disabilities and their families) were clearly biased by the local research coordinators and the folks who came to work with us—because if we hadn't worked with Calvin and had worked with someone else, that person might have identified ten different families. So it's not that it invalidates what we learned from the families that we did work with, but how to present it scientifically and talk about it. Yes, it's a limitation. It certainly doesn't negate, but what does it mean? So I think this is a really important piece. It has been talked about so much in terms of subject population but not in terms of this key informant question.

Dr. Spero Manson: I appreciate this reflexivity—adopting and maintaining a constructively critical perspective on what you do. One of my mentors said, "When you begin to get comfortable, that's when you ought to begin to suspect what you're doing and use that as a device to begin to remonitor what you're doing." You know how it is: you hear a couple of catch phrases and you see a couple of issues pop up and you think, "Oh, I know where that's going right now," and you leap on ahead. So I really try to use that as a red flag: "Whoa, wait a minute, what kinds of assumptions am I making here? Let me continue to be critically reflexive about that." We don't talk about that. We don't write about that. We don't often admit other people to that degree of the internal workings of our own reflection on what it is we do and how we go about doing it.

It's important that we begin to do that. My personal and professional opinion is that there is bias in everything we do. The only protection we have against that is this critical stance of reflecting frequently about what the nature of the biases may be, and inviting other people into that dialogue. In our work with our field office teams in the six or seven different tribal communities with which we work, we invite that kind of critical discussion. In some places it's easier than others, but this is part of the perspective that you need to encourage and maintain. And sometimes it doesn't feel very good. It's like when you do performance evaluations. We've started doing evaluations where those of us who have subordinate employees rate them and then they also rate us as supervisors. I would carry that model forward into our working relationships with our community partners. We have to develop methods that encourage and promote that kind of perspective in the dialogue, but in pretty low risk situations. The high risk situation is when you get in front of the tribal council and have everything riding on it. You can do a lot of homework in advance to reduce the likelihood of failure in those kinds of settings. This critical reflexive

process is a part of it, but it's very difficult to talk about. Witness my stumbling around right now. I don't honestly remember, Catherine, seeing any of us write about it.

Dr. Jamie Davis: I wanted to thank you, Spero, and certainly everybody else, for expanding my way of thinking about things. I hadn't thought about the fact that researchers and academicians who are Native or from other indigenous cultures have so much trouble moving up the ladder in the ivory towers and conducting research; I was really touched by that. It made me think—and I hear this theme over the last few comments—we really have to change this. We can't say that just because it has always been done in a certain way it's acceptable. Just like the changes from the DSM-III to the DSM-IV, just like the changes of being open and willing to dialogue and listen, it takes risks—and I think we need to take these risks to change. I think we're getting more support to be able to do that.

If we don't take the risk to change, change will happen anyway. It's just going to be a lot more painful than if we actually put ourselves out there and have open dialogues and be willing to listen to what other people have to say, even if it hurts sometimes. So I just really wanted to thank you and highlight that idea—that we need to make a lot of change, not only in doing research but in how we can support those who are doing the research in our communities.

Ms. Katherine Sterling: The problem, it seems, is not being able to get out of the confines. We need to begin to bring other people and other disciplines into the research. We've been seeing advocacy—in which I include spirituality—as separate from science. This has been a long-time problem, because there are no confines, and truthfully they are hand-in-hand most of the time.

Dr. Spero Manson: You're absolutely right. In my division we have 110 faculty and staff, with 18 different disciplines represented. We can't hope to understand comprehensively any of the issues that we face if we focus exclusively from any one disciplinary orientation. There are those of us who are community-oriented, who have to understand the special context, the social and physical environment in which we Native people live. Then we have to have psychologists and others who understand psychiatric stresses at the level of the individual. We have to have the more public health-oriented individuals and some of the family therapists to put into perspective family dynamics. And increasingly, as we're beginning to understand the interaction between biology and sociology, we need to have as part of our interdisciplinary teams those more biologically and genetically oriented perspectives to help us understand those processes as well. We can think of this not only in terms of community-based participatory research but in terms of having other disciplines represented when we work through our community partners.

You characterized yourself a little earlier as a theologian. Well, our traditional healers represent those multifaceted perspectives in our communities—and it was, in fact, those individuals in the veterans project I mentioned earlier who pushed me to include the spiritual and traditional healing dimensions. Do you know what the great irony was? They were absolutely right, because based on the data from that particular project, the Veterans Administration—mind you, the arch-conservative of federal agencies—signed an agreement in April of 1998 with the Navajo Nation, so that it now funds any one of 13 tribal ceremonials done on behalf of Navajo veterans. This just underscores for me that the wisdom is there if we're open to listening to it and asking for it.

So I embrace your notion of cross-disciplinary work. I don't think it's a panacea, but I think it's an important one of the tools available to us.

Dr. Paulette Running Wolf: I really appreciate your comments and I agreed with them fully in terms of the [paper] we worked on. On the question of why it didn't work before, in the

70s and 80s, I think the issue is that we really need to build capacity. Not only tribal councils taking on responsibilities, communities taking on responsibilities. We need to assist in that process, and it's an education process. I think that's what you're describing, that this process has been occurring over the years—and maybe it is culminating. It is exciting to see this kind of thing happen.

Your last point is the tension. We really need to be aware of the tension. Just the process of writing the paper, speaking yesterday in the panel—at least for a Native person it's always a struggle. I still haven't published the research on my dissertation—Blackfeet values.

Dr. Brigitte Manteuffel: I thought that your comments were right on about the tension. I know I've experienced it in the work that I've done with the national evaluation and what I've learned over the three years that I've been with this project—in terms of what is required of us as evaluators, the perspective that the outside world has of us as evaluators, and what we internally go through in thinking about how we bridge the path between a national evaluation, which has this broad-reaching agenda, and at the same time have that be meaningful locally. And actually questioning every day, at some level, whether what we have created through this process is ultimately meaningful and valuable, when you have such a diverse group that you're representing with one model. I have thought a great deal over the last two years about how you can build a model that would be meaningful and meet the national agenda and also meet the local agenda, given the issues associated with good research practice from a quantitative perspective.

Something else that has struck me yesterday and today is something that, Spero, you started with your comments on Jamie's paper; it has to do with subjective and objective relationships. One of the things I got out of Jamie's paper was the articulation that when we think about working with communities in a participatory process, it is not just from the research perspective but also from the program perspective. Working with the family members in the comprehensive child mental health program, we had to pay attention to the family members saying, "We need to be at the table. We need to be right there. We are a partner in this process."

I've heard a lot of language that sets that relationship between the subjective and the objective—we call it "us and them." What I've come to believe is that we need to be thinking about partnership and collaboration and participation, so that we're not thinking in terms of "the observer and the observed," the "us and the them," but we're thinking about the "we"—and that we incorporate that in what we're doing.

Dr. Spero Manson: That's a necessary but not sufficient step. Part of it is that you also have to share the power.

Dr. Brigitte Manteuffel: I do think that we have to think about the sharing of the power and remember that. We encounter that all the time. If we don't think right from the start about sharing power in the activities that we want to do with specific communities or specific communities want to do with us, we always run up against a problem.

Ms. Jill Shepard Erickson: Maybe this is a naive statement—but I don't think it should be: it seems like the tribal colleges would be the vehicle for developing local IRBs.

Dr. Spero Manson: Tribal colleges are in different places and there's a great deal of variability among them. Some are ready to do that, and have stepped forward, and have done it; others just aren't there yet. It's a reasonable vehicle, but again, it depends upon how the TCU [tribal college/university] is chartered in the local community. We work closely with four or five TCUs in communities; in some cases there are good relationships between them and the tribal council and in other cases there are not. There can be battles about

jurisdiction and primacy of authority. So TCUs are a good place to look. I don't think they necessarily will always be the best options, but I think it's an important area in which we should continue to invest our energies, because that's where a lot of this capacity will spring from, ultimately.

Summary and Overview for Day One

Holly Echo-Hawk, M.S.
Facilitator

What an interesting day. I thank you all again for your time and hearts and brains and experience. I was thinking of the diversity and the experience that are in this room. You spoke earlier, Spero, about the lack of a critical mass in the past. It's very exciting to see this group, and to know of even more people who are not here, perhaps. It's exciting to see that critical mass is developing.

In listening to you all, reading the papers, and listening to all of the discussion, it strikes me that the work you all are doing and the purpose of this is parallel to the whole movement of cultural competency. You all work at what is called "cultural consideration" in the AIRPEM background materials. That whole movement, from cultural awareness and cultural consideration, ultimately to cultural competence and cultural proficiency, is very much a parallel piece to what you all are discussing here.

The other theme of today certainly has been the term that you're using, Spero, of "tensions." I think that is a very powerful theme, and really reflects the struggle that continues and that you all have articulated so well. The cultural assumptions, the scientific tensions, as you used the term, Spero, and the assumptions or fit with the local communities is a huge challenge.

The other piece I was struck with is the discussion about whom you all are partnering with for your research efforts in local communities. There is the whole issue of historical trauma. And as you're talking about whom you're partnering with in local communities, the challenges of tribal council folks, and all of those factors of partnering with local people but not necessarily being certain of what their agenda is, and their own personal history, their own personal readiness to be able to partner and represent and speak for a broader group of folks—this is frequently in the discussions that some of the other tribal folks have been having. It goes all the way back to the untouched topic of historical trauma and the impact it has had on the individuals in the community generations later.

This discussion you all have had about the relationship of research to advocacy, and the legitimacy—or not—of the researcher-as-advocate role, and the question of whether or not researchers are equipped, as Spero was saying, to take on that advocacy role, is just a fascinating topic.

What I hear you all talking about is the need to have community involvement from beginning to end—really being able to "walk the talk," as I call it. And that is in a sense complicated by the discussion of where your collaborators come from. The political and social context—I thought, Walter, you did such a fabulous job of discussing that in your [paper]. It is a tremendous challenge in the work that you all are doing, and I really applaud you all for the energy and, again, the brain power, the heart power, that you're putting into this.

Another category of the discussion that I've heard this afternoon is exploring ways to bridge the "us against them." This may be a growing critical mass but it's still very small compared to the larger scientific community that has tremendous power and influence. I think, Spero, you were speaking to how critical it is to share not only the power but to share also the resources, and the development of not just partnerships with the local tribal communities but of *authentic* partnerships. I think that term "authentic" is a very important word, because a lot of times it's easy to say you have a partnership when, in fact, that level of authenticity of how it actually plays out may be a whole different level that many folks need to move to.

Focus on Cultural Issues in Research: Developing and Implementing Native American Postcolonial Participatory Action Research

Joseph B. Stone, Ph.D., CAC Level III, ICADC

Dedication

Mike Desjarlais: February 1960—August 1978

Of all my family members, you have been the one who has often crossed my mind, and led me to wonder who, what, how, and, most poignantly, why... So, I've asked our brothers and our father that question. Our father said that it was a puzzle and that you were watching that DeNiro film, The Deer Hunter, *over and over. One brother remembers a strong-willed and independent little boy and said you had a look in your eye that didn't fit in the last photo he saw.... He still sees you in his dreams. One brother remembers that you were always playing tricks on people and full of humor...you were supposed to be together with him the next weekend and the event was all shrouded in controversy and mystery.*

For me, it was the wondering why that came with a sense of loss...and I realize that in part asking myself why has shaped who I've become. I thought a lot about Native people and their losses and the manner of these things. So, I've written down what I think begins to answer the why, at least for me, in this paper. This paper is for you, little brother, and it is for all the injured young Native men and women who have chosen to take the path of suicide. In beginning to try and understand why, I hope I am honoring you...all of you. The Shawnee poet wrote about an elder, Horse Man, who had passed over:

> *I have seen the rain speak and the wind dance. I have seen the lightning knife cut the sky. I have seen the hills at the first light of day whispering secrets in the Southwind People's ears. I am happy now. I am no longer thirsty. I dance a warrior's dance. I am not sick, I am free! This night I dream a new dream! Now, I come to drink the stars! (Jennifer Pierce Eyen, 1997)*

In time, we will dance that warrior's dance together..."Ike."

Joseph B. Stone

Clearly, Indian Country presents even the most seasoned and careful researcher with numerous methodological issues. Two of the most salient of these methodological issues represent complex and interwoven challenges: 1) appropriate understanding and acknowledgement of postcolonial stress in the tribal communities, and 2) the use of participatory action research methods and models in a culturally sensitive manner (Brown & Tandon, 1983; Brydon-Miller, 1997; Duran, 1984; Duran & Duran, 1995; Locust, 1995; Lewis, Duran, & Woodis, 1999; McTaggart, 1991; Park, 1999; Walters & Simoni, 1999;

Weissberg & Greenberg, 1998; Whyte, Greenwood, & Lazes, 1989; Wisner, Stea, & Kruks, 1991; & Yellow Horse Brave Heart, 1998).

While it is beyond the scope of this critique to describe fully the postcolonial stress theoretical perspective, we must briefly acknowledge the issues of trauma and grief, which robustly impact tribal peoples across and within generations. This has led to Natives and tribal families being immersed in an intergenerational and intragenerational crucible of stress. Thus, it follows that a higher level of posttraumatic stress within First Nation individuals, families, and communities, and also secondary consequences similar to those exhibited by Jewish Holocaust and Khmer Rouge survivors, exist as a result of postcolonial stress (Last & Klein, 1984; Nadler, Kav-Venaki, & Gleitman, 1985; Rowland-Klein & Dunlop, 1998; Sack, Clarke, & Seeley, 1995; Yehuda, Schmeidler, Elkin, Wilson, Siever, Binder-Brynes, et al., 1998). Consequently, a high incidence and prevalence of psychiatric disorders and social problems, per se, lateral violence, and high rates of substance abuse secondary to posttraumatic stress are observed in indigenous peoples (Ball, 1998; Gagne, 1998; Nagel, 1998; Weaver & Yellow Horse Brave Heart, 1999). In 1992, Herman suggested that the symptoms of a sequelae of prolonged and complex trauma across time on psychological functioning might be very significant. The primary effects of this sort of stress in the lives of long-term sexual abuse survivors and combat veterans are a highly coherent description of many of the symptoms and issues faced by tribal people (Ford, 1999; Ford & Kidd, 1998; Zlotnick, Zakriski, Shea, & Costello, 1996). At this point, I would like to discuss the methodology for this review.

Review and Methodology Procedures

The primary task for this critique was the review of papers provided to the author prior to their presentation and discussion at the recent American Indian Research and Program Evaluation Methodology Symposium, and published in this monograph. In addition, the author reviewed two recent Fisher and Ball (2002a, 2002b) articles on postcolonial (or tribal) participatory action research, the reference lists of several recent books, several review articles, and various other published studies and documents, and also manually searched several recent journals. Keywords included *posttraumatic stress, postcolonial, intergenerational trauma, unresolved historical grief, resiliency, attachment, neurodevelopment, developmental psychopathology, participatory action research,* and *collaborative community research.*

Numerous studies, articles, and books were located that contained relevant information referenced in the body of this paper. The author used the postcolonial stress theory and the postcolonial participatory action research model proposed and described by Fisher and Ball (2002a, 2002b) as the basis for developing a coding instrument that was used to analyze the reviewed papers. It is important to discuss research and evaluation methodology in First Nations communities within the context of a postcolonial stress theory.

Next, I will describe the general background of the postcolonial stress disorder theory as it applies to tribal people, and then move to a brief discussion of my personal theoretical perspective on the origins and implications of postcolonial stress in tribal individuals, families, and communities.

Postcolonial Stress Disorder

Intergenerational Postcolonial Stress and Tribal Families in Stress: Neurodevelopment, Developmental Psychopathology, Reactive Attachment Disorder, and Compromised Behavioral Immunity

Brain Development in the Child

Clearly, the literature in the scientific area of attachment and infant mental health is vast. It is not my goal herein to offer a complete theoretical discussion of attachment, regulation, or infant mental health. Rather, I am

providing a simplified version of this complex area as a heuristic mechanism to initiate further discussion of the issues central to attachment, self-regulation, and infant mental health as a possible mechanism to describe the occurrence of postcolonial stress in tribal peoples. It is not my goal to suggest that this perspective on postcolonial stress is right or correct; it is my goal to suggest that it might be considered and investigated for potential value as a possible correlate to postcolonial stress. It is possible that the description of tribal history might have a relationship with attachment, self-regulation, and infant mental health that has some descriptive value as an influencing factor in postcolonial stress. Further, perhaps researchers should consider taking postcolonial stress into account as an important variable in developing a participatory research agenda with tribal communities, even if this description of the possible relationships of attachment, self-regulation, and infant mental health ultimately fails the scientific test.

Recently, B. Perry (personal communication, May 1, 2002) asserted that the first four years of life are the most critical for brain development of the child. Borrowing from a description given by Perry, I would like to provide a simplified description of brain development during the first four years of life. Initially, the infant's cognitive abilities are limited by the not fully developed prefrontal cortex and nerve fiber system that are involved with thinking and memory (representation of visual and verbal experiences). Neonates appear capable of storing and retrieving sensory information even delivered to them prenatally; however, lacking speech, they are unable for some months to engage in the type of inner speech that one might characterize as thought. During this initial period of time, the infant is capable of feeling arousal because the limbic system is well enough developed to generate feelings of arousal (Nieuwenhuys, Voogd, & van Huijzen, 1981; Papuz, 1937).

I believe that one important goal of infant behavior is emotional regulation, which is the effort to find calmness through control, modulation, and mediation, when unmet needs or noxious environmental events cause an uncomfortable arousal state, thus achieving homeostasis or "emotional balance" (Post, 2002). Thus, some of the reasons infants cry include signaling their experience of painful arousal to the caregiver in order to be fed, cleaned, or when they are otherwise uncomfortable (Post, 2002). Self-soothing behavior is a complicated area to discuss and understand; perhaps infants learn to self-soothe by recalling a representation of the caregiver, for example, via transitional objects such as blankets, stuffed animals, etc. They might also be soothed by their caregiver's voice (prosodic verbal memory) and items of clothing that smell (olfactory memory) like the caregiver. Perhaps one critical aspect of the infant becoming capable of self-regulating its internal limbic system-mediated arousal is that this capability is learned through the type of response that the infant receives from caregivers or parents to its signals of need (Schore, 1994; Stern, 1985; Greenspan, 1981).

In general, although the range of caregiver responses to children's needs is quite wide, I would like to point out the effects of the two polar extremes of caregiver response to the infant's development of a capacity to control or modulate its own arousal. These polar extremes are the responses of *adequate caregivers*, who equitably meet the child's developmental needs for care that facilitates adaptive brain development, versus the responses of *inadequate caregivers*, who do not adequately meet the child's developmental need for care that facilitates adequate brain development. Additionally, there are "difficult to soothe" infants who present temperaments that challenge adequacy in caregivers, as well as reverse socialization processes that include "slow to warm" infants who leave caretakers feeling rejected and gradually less willing to be involved in attachment and bonding behavior with the infant. In the next section, I would

like to consider a simplified description of adequate caregivers and the implications for child brain development.

The Implications of Adequate *Caregiver Behavior for Child Brain Development*

Consistent caregiver response to a child's expressed needs and the caregiver's unconditional attention to the child are likely the most significant and important features of caregiver-child interaction underlying adaptive brain development of the child (Noshpitz & King, 1991). For example, if a child cries when in an arousal state related to a basic need (food, comfort, safety, etc.) and the caregiver responds in an adaptive and beneficial manner, the child becomes calmer and over time more capable of self-regulation (soothing itself or modulating its own limbic system-mediated level of arousal). First, the caregiver provides the desired or needed items or care. It is likely that of greater importance to the child's adequately developing the capacity to regulate arousal (soothe itself) is the effect of the caregiver's contact and soothing behaviors during the interaction (Amini, Lewis, Lannon, Louie, Baumbacher, McGuinness, et al., 1996; Gazzaniga & LeDoux, 1978; Heineman, 1998). A caregiver who consistently picks the child up and holds the child close and who is simultaneously in a relaxed and calm state will physically impart that regulated state to the child. The child will synchronize and regulate heart rate, breathing, and state of muscle tension to those of the caregiver. Thus, through the child's experience of being held and soothed, its brain is repeatedly stimulated in the process of self-soothing or regulation of arousal that parallels the regulated state of the caregiver. Over time, with consistency, as the child's brain is developing, this process becomes second nature to the child (e.g., simultaneously, the brain of the child develops the capacity for self-regulation of arousal and the process of self-regulation of arousal is learned) (Schore, 1994). Of interest, simultaneously, the development of the child's prefrontal cortex and the innervation of the brain (growth of nerve fibers connecting various areas of the brain) is occurring during the first few years of life. This process of brain development and innervation underlies the development of various areas of the brain communicating with and signaling to each other with biochemical neurotransmitters. Thus, neurodevelopment leads to communication between the prefrontal cortex and the limbic system (Schore, 1994; Birch, personal communication, June 4, 1999).

This is tremendously important, because simultaneously with the developing capacity for self-regulation developing during consistent caregiver responses, the child is also developing the capacity to maintain a set of internal verbal, visual, and auditory images (stored and integrated in the prefrontal cortex). Clearly, these processes are dependent on approximate ages and sequences of development. Receptive language precedes expressive language, sometimes by years in boy infants. Therefore, the question arises, how does understanding speech at 10 months help in self-regulation? For example, a mother smiles and says "no" gently to a 10-month old daughter and the baby clearly stops, smiles, and hesitates, watching the mother carefully. In this case, the mother did not have to regulate the child herself, using body contact, and apparently speech extended her range of interaction as well as the baby's ability to self-regulate via understanding of the verbal cue. The complexity of how a child can develop the capacity to integrate and control self-regulation through improved communication between the prefrontal cortex and the limbic system, based on the growth of nerve fibers connecting these areas of the brain, is indeed a complex process that exceeds the scope of this paper to describe. Apparently all aspects of the caregiver and the context of the care become associated with increased capacity to self-regulate arousal. Thus, the child can then produce internal visual, verbal, and auditory representations of safety and care that are learned during interactions with the caregiver. The child integrates these representations of visual, verbal, and auditory stimuli in the

prefrontal cortex and attaches meaning to them. This process becomes the basis of a biochemical and electrical message from the developing prefrontal cortex to the limbic brain through the newly developing connective nerve fibers. It is likely this complex developmental process of caregiver-child interaction occurring simultaneously with brain development that underlies a child's capacity to self-regulate arousal (Emde & Buchsbaum, 1989; Fair, 1992; van der Kolk & Fisler, 1994). Two of the most critical aspects of this developmental process of self-regulation are that 1) the caregiver is consistent and available to facilitate the developmental process of self-regulation, and 2) the caregiver is capable of self-regulation and is consistently and predictably self-regulating her or his arousal during this developmental process. Adaptive parenting is likely adequate facilitation of child attachment.

There exists a polar opposite in parenting style, which is the inadequate caregiver model, contributing to development of dysregulation of arousal. Perhaps chronic dysregulated arousal in a child can be described as reactive attachment disorder and the issues that surround the dysregulation of arousal of might be a product of caregiver-child interaction.

The Impact of Inadequate *Caregiver Behavior on Child Brain Development*

The scientific literature is clear: there are several types of caregiver behaviors that are inadequate, per se; excessive anxiety, depression, substance abuse, and psychotic process in the caregiver underlie the expression of psychopathology in the child and developmental psychopathology as the child ages and grows (B. Post, personal communication, June 25, 2002). Of course, it is equally reasonable that within families affected by or functioning within stress, caregivers in stress act as the primary facilitators of the children's development. Therefore, I believe that in addition to caregivers with defined psychiatric conditions, such as those discussed above, the caregivers in families impacted by ongoing stress are also often rendered inadequate in their provision of developmental care to the children in these families by the stressful conditions impacting the families.

Caregivers who have anxiety, depression, or substance abuse on board are less consistent, are less capable of self-regulation, and thus are less capable of providing an adaptive developmental experience during the aforementioned critical period of child neurodevelopment. Within families impacted by stress or families where the caregiver is compromised or inconsistent, the child does not receive the type of consistent care needed for self-regulation of arousal. Additionally, in many cases, caregivers in these types of families are themselves not as capable of self-regulation. Therefore, the child cannot directly experience an adult model of self-regulation while in direct contact with an adult who is capable of self-regulation. Thus, the child's brain cannot fully develop a capacity for self-regulation of arousal.

I believe that inadequate caregivers can not provide the child with a consistent experience in self-regulation because of depression, impairment by substance abuse, or extreme anxiety and concurrent incapacity to self-regulate arousal. Consequently the child experiences an inconsistent process of what it means to be soothed, and it follows that the child develops an inconsistent ability to regulate arousal. Often, children with inadequate or inconsistent caregivers receive care in intermittent spurts of stimulation. Therefore, these children often do not develop the capacity to regulate arousal in a consistent manner. These children's limbic systems actually do not develop the capacity to regulate arousal consistently as a result of inconsistent stimulation during childcare.

Caregiver attention that comes in spurts of stimulation (positive but inconsistent and/or varying to negative) subsequently conditions the child to regulate arousal by engaging in a stimulation-seeking process. These children

become indiscriminate in the types of stimulation that they might elicit to activate arousal-regulatory mechanisms in their limbic systems. Many times children conditioned indiscriminately "act out" in a manner that elicits negative stimulation or punishment, because this is equally effective in helping them activate their capacity to regulate arousal. In these situations, the child acts out in order to be punished or abused, because even that type of response stimulates the brain to dampen uncomfortable levels of arousal (to self-regulate).

Of course, if inconsistent caregiver attention creates a limbic response that is sensation-seeking as a means of stimulating regulation, there is an unfortunate additional effect to the developing prefrontal cortex and innervation. That is, the verbal, visual, and auditory images of the caregiver and environment that are integrated into meaning in the prefrontal cortex are disjointed and inconsistent (Brown, 1991; Coen, 1985; George, 1996; Krystal, 1990, 1991; Green, 1995; Dubowitz, Black, Harrington, & Verschoore, 1993). Furthermore, in addition to the fact that the verbal, visual, and auditory images that stimulate the flow of chemical and electrical messages that are designed to control limbic arousal might exist in this disjointed manner, the actual set of nerve fibers is smaller and less robust. That is because the development of these nerve fibers is dependent, in part, on adaptive developmental care (Rakic, 1991).

The child receiving inconsistent care develops a limbic system that regulates arousal based on stimulation that is both positive (adaptive behavior) and negative (maladaptive behavior). Additionally, these children often have cognitive distortions about what represents appropriate stimuli for regulation of arousal. Finally, they often must seek intense stimulation in order to create a biochemical and electrical message of great enough magnitude to overcome the deficient nerve fibers connecting prefrontal cortex and limbic system.

There is a second problem that children experience from care given by adults who can not control their own arousal. These children can not develop the process of self-regulation because they have no model or contact with another human who is self-regulated. These children must replicate the level of self-control and self-regulation experienced by their caregiver. If that is limited, the children's capacity to self-regulate arousal is limited. We are aware that this has long-term implications because if the critical period of brain development passes, then it is likely that these children will always have greater difficulty with regulation of arousal. One model for understanding this is recent research on the children of depressed caregivers versus the children of nondepressed caregivers. On a brain scan study of infants of depressed caregivers, the infants had similar responses to the depressed caregiver walking *toward* them as infants of nondepressed caregivers had to their caregiver walking *away* from them. It was postulated that these infants might have experienced dysregulated arousal during interactions with depressed caregivers (B. Post, personal communication, June 26, 2002).

Obviously, children with inconsistent caregivers or caregivers who could not regulate their arousal become adult clients with up and down behavioral phases across time of living well, not living well, living well, not living well. Falling in love, falling out of love, falling in love, falling out of love with very exciting and toxic people who are highly stimulating. Adults who get themselves into risky situations as a mechanism to stimulate modulation of arousal. Perhaps they jump out of airplanes with parachutes for fun. Perhaps they engage in high-risk sexual escapades in order to have the type of stimulation that helps them regulate their arousal. Perhaps they engage in substance abuse in order to use the derivative chemical interactions secondary to substance abuse as a mechanism to regulate arousal.

Often when children have had inconsistent parenting in infanthood, as adults they seek stimulation, they ride on this wave of stimulation, they must have stimulation in order to regulate arousal. But that stimulation is not necessarily provided by consistent, healthy, or adaptive behaviors. Furthermore, the child whose early capacity to self-regulate is compromised by inconsistent or unregulated developmental interactions with the caregiver is set up to be an adult susceptible to anxiety, depression, and consequently substance abuse. I call this result of developmental process *compromised behavioral immunity* (CBI).

Compromised Behavioral Immunity

Initially, I became aware of the phenomenon of compromised behavioral immunity as I worked with war veterans and victims of violent sexual assault as adults. In both of these populations, I found that the impacted individual might have a very similar experience to his or her peers. However, some individuals responded well to treatment and improved rapidly, but others did not. As I became more aware of the clients' individual histories, I saw a trend emerge. Individuals who appeared to make good progress in therapy and to improve from treatment usually reported much more adaptive developmental experiences as children and adolescents. They usually had adequate caregivers and usually were not impacted by as many or as intensive a set of developmental insults as adolescents. On the other hand, individuals who reported experiencing inadequate caregivers as children usually exhibited a greater magnitude of psychiatric symptoms as a result of war experiences or adult sexual assault. I term this phenomenon compromised behavioral immunity (CBI), which is the result of the impact of inadequate early developmental experiences on resiliency in adulthood.

Compromised behavioral immunity (CBI) seems to reduce resiliency in adults, and thus underlies the expression of psychiatric disorders of greater magnitude. The experience of families in stress (wherein the adults are not as available to facilitate child brain development) and families with caregivers who have psychiatric and substance abuse issues describes the milieu of development leading to dysregulated arousal, reactive attachment disorders, and compromised behavioral immunity. This was the crucible of child development for tribal families and their children across the past five hundred years. I believe many psychiatric and substance abuse issues of postcolonial stress emerge from and are described by the following model of colonial impact on tribal communities, families, and individuals.

Postcolonial Neurodevelopment and Developmental Psychopathology In First Nations Communities

The theory of neurodevelopment sketched above is greatly simplified with respect to the large body of scientific literature that is available, and a complete description is clearly beyond the scope of this paper. However, perhaps this simplified model of attachment, self-regulation, and infant mental health has some descriptive value when integrated into a postcolonial stress model. I think we need to marry our concepts of historical trauma, the postcolonial mechanisms that have shaped tribal communities and families, and the impact of these events and systems on the development of tribal children across generations. Understanding these interrelated phenomena and dynamics leads to understanding the neurological impact of what being a tribal person in this country has brought to each and every one of us who are tribal people.

This model describes a simplified version of neurological development and human development in the Native community across the past several generations. Further, one must bear in mind that this postcolonial stress model demonstrates the tremendous resiliency and strength of survival demonstrated across the generations. Perhaps one reason that this resiliency and survival in the tribal community is evident is related to the strength of tribal spirituality.

Another thing to remember is that the events discussed within the various generations in this section are examples of ongoing processes, so the reader must consider that the negative and oppressive dynamics described herein and experienced by our tribal ancestors are in many cases continuing for contemporary tribal people in the U.S.A. Finally, it is important to note that this postcolonial stress model of intergenerational neurodevelopment and developmental psychopathology can likely be adapted and applied to other indigenous colonized populations, such as New Zealand Maori, Australian Aborigines, South American Indigenous, and South African Blacks.

This intergenerational postcolonial stress model of neurodevelopment and developmental psychopathology secondary to colonization and compromised behavioral immunity in the tribal communities is by no means representative of any given individual Native family. I initially thought about this intergenerational postcolonial stress model as it applied to understanding my personal tribal family history for heuristic reasons. Following my professional training, I later integrated scientific aspects of the postcolonial stress model and generalized the theory. I think the generalized postcolonial stress model is somewhat representative of most tribal people's developmental experiences, even given the need for a more robust examination and subsequent integration of attachment, self-regulation, and infant mental health literature if warranted. Furthermore, it is clear that a growing number of studies support the idea that intergenerational transmission of attachment and attachment problems exists (van Ijzendoorn, 1995a, 1995b; van Ijzendoorn & Bakermans-Kranenburg, 1997; van Ijzendoorn, Juffer, & Duyvesteyn, 1995; Zeanah, Finley-Belgard, & Benoit, 1997).

Dispossession and Biological Warfare

I'll start my description of postcolonial stress in the early 1600s on the east coast and with the first colonization of this country. Early in the colonization period tribal people were dispossessed of property: the enforced movement of Native people from the prime country in which they lived. Tribal people experienced forced moving from the places that they loved and were spiritually attached to. Of course, dispossession was almost always enforced at musket point and with violence.

Beginning with early tribal dispossession, we can begin to see correlation with posttraumatic stress in the dispossessed Native communities, families, and individuals. I assume that the first generation of dispossession, which occurred in the eastern coastal area of the U.S in the 1500s and 1600s, began inducing anxiety, in the form of posttraumatic stress, into the tribal community.

Occurring simultaneously with tribal dispossession was the biological warfare that began to occur back in that era. Biological warfare also introduced anxiety in the form of posttraumatic stress disorder into tribal communities, families, and individuals. The colonizers distributed blankets infected with smallpox and other foreign bacteria and viruses to decimate tribal communities. Initially, that type of biological warfare killed a lot of Native people outright. It also made the communities, families, and individuals less capable of engaging in their customary economic and social process. It destroyed our Native communities' capacity to engage in the economy, that was mainly gathering and hunting. If a lot of the gatherers and hunters are down and sick and dying, they can't gather and hunt. If the other tribal people are helping them, then these other Natives can't gather and hunt while providing care to the sick.

This early biological warfare conducted against the Native communities was very destructive to traditional child-rearing patterns and to the tribal knowledge base. It was very destructive of our tribal knowledge base because our Native libraries were the elders, who kept tribal knowledge in the form of oral histories. The elders were most susceptible to disease, and thus our historical knowledge that

stretched back as an oral history for centuries was devastated by this biological warfare as elders died. The biological warfare also devastated children, because they were young and susceptible to infection.

In some tribes, when children were born the parents took a whole year just to nurture that child. Other tribal members hunted and gathered for them while the parents just took care of their child. Then at the end of that year the child was turned over to the tribal elders and was raised to become who they would become. The tribal elders would choose to teach the child what he or she would need to learn to optimally function and support the tribe. So you can imagine the effects of biological warfare impacting these two portions of our tribal community.

The most pernicious effect of the biological warfare was its impact on tribal spirituality. In our First Nation communities the capacity to cope with difficult situations and/or health crises was enhanced or made greater by our Native spirituality. Our tribal spirituality was tied in to the context within which it was practiced. Native spiritual practices, such as smudge, or whatever we burned, the smell of that, the chanting, the drumming, the use of tribal medicine, and the presence of tribal healers all occurred in an environment where indigenous people were confident that it influenced healing. When the spiritual ceremonies and practices that enacted healing would occur, of course healing would follow, because those ceremonies and practices would activate the tribal member's immune system. People were confident that they would get well. Their immune system would be enhanced by a ceremonial and so they would get well. However, when a foreign microbe invaded the tribal community, the tribal member's immune system could not cope with that foreign microbe. Therefore, even if an enhanced immune function occurred in a tribal member secondary to a ceremony, the person still did not get well because the immune system could not cope with the microbe. In fact, even, the most highly respected medicine people and healers could not help others or themselves. So, we saw the abrupt and total failure of tribal spirituality to activate the immune system and help Native people deal naturally with the microbes introduced by the colonizers. Of course, the same tribal spiritual practices were used to cope with emotional disturbances secondary to the trauma of illness and dispossession. Consequently, when their tribal spiritual practices were disrupted, what coping mechanisms would Native people turn to for emotional coping?

I think that whole process of tribal lifestyle, health care, oral history, child rearing, and emotional coping was extremely disrupted by the biological warfare that was initiated about 500 years ago. Of course, in addition to these effects of biological warfare in the Native community, individual tribal people developed posttraumatic stress disorder as a result of their family members dying around them.

The First Generation of Anxiety and Depression Secondary to Colonialism

Of course, posttraumatic stress disorder is an anxiety disorder that exists on a continuum with depression (at the opposite polar extreme). Furthermore, subjectively speaking, anxiety feels very much like arousal. If one is anxious one feels as if one is experiencing a higher level of arousal most of the time. If one doesn't have a coping mechanism to help reduce or regulate that anxiety, one is susceptible to becoming depressed. For these anxious individuals, their experience with anxiety is like a dog sitting on a steel grating getting electrical shocks that it can not escape. The dog jumps as a result of the electrical jolt and attempts to escape. Historically, I think that following a jolt of anxiety tribal people used ceremonial community-based spiritual coping to reduce that anxiety. However, when tribal spirituality was disrupted, these Natives' subsequent experience was similar to a dog receiving uncontrollable electrical shocks but unable to escape them. Every time something happened to the Native person, that person's

anxiety rose with nothing to control it. Soon, no matter how hard electricity hits the dog, he just lies on the grate. In parallel, the tribal person continued feeling a lot of anxiety but could not regulate it with the accustomed spiritual practices. These Native people felt helpless to regulate their anxiety. Tribal people began experiencing a shift in the anxiety-depression continuum. They developed depressed mood stemming from uncontrollable anxiety that was no longer ameliorated by use of tribal spiritual practices as coping mechanisms.

So, during this generation, the first generation of colonization, we really start to see our first tribal people experiencing anxiety and depression disorders manifested in the families and in the caregiver's behavior toward the children. Furthermore, these tribal families were in continual stress from other external factors predicated on colonization.

It is logical that parents who are in a crucible of family stress, such as oppression, racism, warfare, and other factors predicated on colonization are distracted from their children and child-raising practices. These tribal parents were distracted by anxiety and unavailable because of depression. Thus, this generation of Native parents became less than optimal caregivers for the children's developmental processes. So, we have our first generation of colonized effects on tribal families (families within which ongoing stress, anxiety, and depression are manifested). Of course, the dispossession and biological warfare are ongoing processes across the eastern seaboard, so it is highly likely that most tribal people are affected. If most tribal people are affected, then most young tribal people who marry and have children become families in stress, with these new parents having their own issues from becoming the first generation of Natives manifesting anxiety and depression as a result of the effects of colonization.

This is our first generation of colonization-impacted Native parenting practice. By definition, we have established that children who receive parenting from inadequate parents (families in stress, anxious parents, or depressed parents) are more likely to manifest reactive attachment disorder or a dysregulation of arousal. This gives us our first generation of Native children beginning to have some dysregulation of arousal, resulting in reactive attachment disorder and compromised behavioral immunity. Postcolonial stress-impacted Native adults (anxious and depressed) are providing parenting within families under further continual colonization stress from external factors.

We have defined reactive attachment disorder as stemming from a high level of unregulated arousal that sets up a child for compromised behavioral immunity and greater susceptibility to developmental insult. Furthermore, we must be aware that the discrete generational events or occurrences we are discussing in fact occurred across generations and are cumulative effects from one generation to the next generation. So it wasn't just this generation of tribal people having dispossession and biological warfare occur. The next generation of Natives experienced the Indian Wars, but dispossession and biological warfare continued during the Indian War period. I will describe the Indian Wars and the impact of posttraumatic stress on the tribal community in a more definitive manner in the next section of this paper.

Neurodevelopment, Developmental Insult, Posttraumatic Stress Disorder, and the Indian Wars

Envision Colonel Chivington on the hill overlooking Sand Creek in Colorado and his pony soldiers in a skirmish line across the bend in Sand Creek. There is a camp of the Cheyenne in the bend of the creek, and it is dawn. Tribal people are getting up and preparing for the day. We see older people (men and women) and adult women and children of the camp getting up and breaking camp at dawn and getting water to start their day.

The fact that there are no Cheyenne men in the camp is why the U.S. cavalry is here. Colonel

Chivington sees this as a political opportunity to "put down an Indian insurrection." The Cheyenne men are off the reservation against the orders of the U.S. government. The Cheyenne men might be hunting because the rations provided to the tribe are not adequate and the people are hungry. Of course, oral historians suggest that the Cheyenne men might be off and engaged in the Ghost Dance religion, which is also against the government's rules.

Colonel Chivington is poised to attack the Cheyenne elders, women, and children at Sand Creek: it is politically expedient for him to prosecute the savages and it enhances his ability to be elected to office. Another famous pony solder, General Custer, tried that route to political office, also, and we saw how that turned out, but that's another story.

We'll envision Chivington's mini-guns on top of the hill overlooking the Sand Creek Cheyenne camp because that's where the colonel, being a good military man, put his mini-guns. Mini-guns are small cannon that are easily hauled by horse team. Of course, the Colonel, being frugal, loaded the mini-guns with grapeshot. Grapeshot was the stuff swept up off of the floor of the blacksmith shop at the fort—bits of metal from shoeing horses, nails, and other chunks of material. You can imagine that since grapeshot was a product of the fort's blacksmith shop it was mixed with large quantities of horse manure. That means grapeshot was very, very dirty and that being hit even in a non-lethal manner with grapeshot could induce sepsis. So, when shooting a mini-gun loaded with grapeshot at tribal people, it was not necessary to hit a Native directly. All that was required was a grazing wound or a scratch, which would induce sepsis or infection (more biological warfare). A Native injured in such a manner might die or lose an arm or leg.

Colonel Chivington sets mini-guns up on the hill overlooking the Cheyenne camp down in Sand Creek. The Cheyenne warriors are gone. The Cheyenne's buffalo hide lodges are not invulnerable to shells and shelling and these buffalo hide lodges can not turn away mini-gun grapeshot. The colonel is on the hill with his mini-guns loaded with grapeshot and he has his pony soldiers in a skirmish line across the river and he orders the pony soldiers to draw sabers because he wants to save on pistol cartridge rounds.

At dawn, when the Cheyenne people are breaking camp, Colonel Chivington orders the mini-guns fired. We hear a round of grape shot sprayed through the camp at Sand Creek that knocks tribal people over immediately, or wounds them with that deadly sepsis-inducing grapeshot so they might die or lose an arm or leg from infection later. Then the colonel sends his pony soldiers across the river with their sabers and they start hacking folks up. Now, this discussion of the Sand Creek massacre is only an example of the type of aggressive attacks on tribal communities that go on across the country over and over and over during the Indian Wars.

As a result of this type of scene, we have two hypothetical young tribal people coming out of the first generation's postcolonial stress-influenced parenting (tribal parents having some anxiety and depression). Thus, two hypothetical young Native people with some symptoms of unregulated arousal, reactive attachment, and resulting compromised behavioral immunity, getting posttraumatic stress as a result of their presence in the Indian Wars. Therefore, we now have a second generation of young tribal parents facing continued externally generated stress, secondary to colonization, and developing internal anxiety and subsequent depression, secondary to the Indian War experiences, impacting their parenting. Since this hypothetical young tribal couple is anxious, depressed, in a social crucible of poverty, dispossession, and forced movement from historical land base, biological warfare, Indian warfare, and disruption of spirituality, culture, and religion, we can assume then that they're not 100% invested in or capable of adequate

parenting. So, when this hypothetical Native couple has their children, they are raising the next generation of tribal children developing with unregulated arousal, reactive attachment disorder, and compromised behavioral immunity.

We are now two generations into this intergenerational process, so what is next on the colonial agenda for tribal people in this country? Since we're going to finish the Indian Wars, what is the next stage of colonial assimilation and acculturation? The next generation of postcolonial stress-impacted tribal people experienced the impact of the boarding schools.

The Federal and Religious Indian Boarding Schools, Neurodevelopment, Developmental Psychopathology, and Native People

Envision sending a young Native male to the federal Indian boarding school system. Let's consider the federal Indian boarding school system. Created by whom? General Richard Pratt created the federal Indian boarding school system for the express purpose of "killing the Indian to save the man." Now, when these Native children are sent to the federal Indian boarding school systems, who become their instructors and teachers? Who is there to teach these impressionable young Native students? Well, as you can well imagine, if Richard Pratt (retired pony solder general) is the superintendent of the newly formed federal Indian boarding school system, then it follows that he recruits other retiring pony soldiers as staff and teachers. So the largest group of teachers in the federal Indian boarding school system is retired pony soldiers: lieutenants, sergeants, enlisted men, etc.

The era of the federal Indian boarding school system continues to have pernicious effects in our Native communities, effects (often political in nature) that are observable even today. For example, Indian policemen enforced attendance of tribal children at the boarding schools. Indian policemen would go to other tribal members' families and forcibly take their children. Of course, in many cases, families resisted and serious fights would result, often resulting in either the death of Indian policemen or of tribal family members. In most cases, the Native children were taken to boarding school, ultimately. In the tribal communities, we still see political effects of that period of enforced boarding school attendance lingering three or four generations. In some tribal communities, we have families with incredible animosities towards one another but no rational reason why those animosities should be occurring. Tribal members who achieve political power often act out these animosities against one another within the political forum, rather than collaborating for the good of the tribe in general. Apparently, they can not overcome their historical animosity derived from the boarding school era, when an ancestor from one family was Indian police taking the child of another family's ancestor. Rather than the source of this dysfunction being tribal, it was the splitting or atomizing effects of the larger culture using one part of the tribe (the Indian police) against another part of the tribe (the families of students forced into the boarding schools). However, the old animosities still exist and are played out to the detriment of functioning in modern Native society.

The first things that happened when tribal kids got to the federal Indian boarding schools were that their hair was cut and they were prohibited from speaking their language, even if that was the only language they knew. These tribal children were put into regiments and into units and into uniforms.

Around the locations of the federal Indian boarding school system there are killing fields or vast unmarked cemeteries. These cemeteries contain the bones of the tribal children who died of broken hearts or diseases because they had been brought together from around the country with no immunity to one another's diseases.

At this point in time, tribal children in the boarding schools experience their first exposure to large-scale amounts of physical

and sexual abuse. Physical abuse was a mainstay of the discipline in the federal Indian boarding schools. As a result, our first generation of individuals return to their tribal communities trained in the boarding schools to use physical violence as a means of controlling family members: children and spouses. Family domestic violence, a product of learned behavior from the boarding schools, becomes widespread in tribal communities. Lateral violence spreads through our Native communities as an outgrowth of the violence practiced against tribal children in the federal Indian boarding school system. Further, clinician experience indicates that situational molesters are usually previously victims of physical abuse and that they molest out of a need for power and control. Thus, a generation of situational molestation or sexual abuse is introduced into the tribal communities as yet another form of learned behavior derivative from the boarding school era.

So, this is the experience of our hypothetical young tribal man in the federal Indian boarding school system: loss of culture, language (the carrier of culture), beliefs, values, etc., and the experiential introduction to physical abuse and subsequent learning of physical abuse as a control mechanism for family functioning. Finally, it is likely that the young tribal member attending the federal boarding school experiences the devastation of identity that accompanies physical (and sexual) abuse. This loss of identity and sense of personal power lead to the expression of powerlessness as situational molestation within the tribal community and family. Situational molestation to achieve a sense of power and control is acted out in the Native community and family as a form of self-perpetuating lateral violence.

Envision a hypothetical young Native woman being sent to a religious Indian boarding school. The religious Indian boarding school was the equivalent of the federal boarding school for the amount of physical abuse used to control the children. One good example would be in Canada, where there is a small reserve; in that reserve there are three generations of people, aged 55-65, 45-55, and 35-45 years. For many years, each of these groups has smaller groups in all the social and political arenas of tribal life, including the schools, the police, the legal system, the health system, and the political system. Never in the history of the tribe could Natives from one of these groups cooperate or collaborate with tribal members from the other groups. There was always dissension and conflict, apparently without reason and certainly to the detriment of tribal functioning in general.

Members of the youngest group of Natives (35-45 years) go into counseling and psychotherapy. In psychotherapy, members of the youngest group of tribal members remember and discuss sexual and physical abuse that they experienced at the hands of the slightly older group of tribal members (age 45-55). So members of the youngest group of Natives begin to sue members of the 45-55 year-old group of tribal members.

As a result of the stress of the lawsuit several members of the 45-55 year-old group of tribal members go for supportive psychotherapy. In psychotherapy, members of the middle group of Natives begin to think about their own abuse at the hands of members of the oldest group (age 55-65). The middle group of tribal members initiates lawsuits against the oldest group of tribal members.

So now we have a whole bunch of lawyers getting into the fray in this Canadian reserve, helping tribal people sue each other and splitting the community up. Of course, all these lawsuits are high profile, so the Canadian government gets in there and they hire a Native psychologist to find out what is going on. The Native psychologist finds out that on that tribal reserve there was a religious Indian boarding school with a domicile. The domicile was a four-story building for the Native children and for the religious group that came in to teach the children.

The religious group lived up on the fourth floor of the domicile. The oldest group of tribal

people mentioned above lived on the third floor, the second oldest group of tribal people lived on the second floor, and the youngest group of tribal people lived on the first floor. It is revealed to the consulting psychologist that as children, the tribal people on each floor were physically and sexually abusive to one another, the oldest children to the middle and youngest, and the middle children to the youngest children.

However, this whole process of tribal children abusing other tribal children derived from and was set in motion by the actions of the religious teachers. Religious teachers would come downstairs and be sexually abusive to the children on all three floors. But, these religious teachers did another thing that was very detrimental to the tribal children's future relationships with one another. The religious teachers used the oldest group of Native children to enforce their will on the second oldest group of tribal children, and used the second oldest group of Native children to enforce their will on the youngest group of indigenous children. The religious leaders set these groups of Native children at one another's throats in order to control them.

As a result, when these tribal children grew up on that Canadian reserve, three distinct political factions emerged in which the people hated one another, were unwilling to talk to one another, and could not collaborate politically for the good of the reserve. In addition, many members of these three groups also acted out in lateral violence: sexual molestation and physical abuse in the community as a result of this happening to them in the religious boarding school.

A really tremendous social problem evolves here for the tribe. Tribal members are acting out lateral physical abuse and sexual molestation against the children of the next generation, they can not cooperate or collaborate with one another at any level, and they are all suing one another. Probably the only good thing that happened was that once this phenomenon was understood, everybody from the tribe did finally collaborate. The tribal people got together and sued the religious group. But unfortunately healing wasn't emphasized in this collaboration. Apparently the hurt was so great that when this tribe started on the path to healing they stopped and stepped back and began the process of disagreement and social disruption again. The tribe couldn't tolerate healing together, so they're sort of stuck right now with this distinctly split-up community, as a result of the influence of their attendance at a tribal religious boarding school.

We have envisioned a hypothetical male tribal person from the federal Indian boarding school with some experience of physical abuse and possibly sexual molestation. Further, we envisioned a hypothetical female tribal member from a religious Indian boarding school with a history of sexual and physical abuse. Perhaps she attended a school similar to the religious boarding school in Canada. We know that people who have been sexually abused have difficulty protecting their children from being sexually abused. People who are physically abused often become what we call situational molesters—not pedophiles, but situational molesters who use sexuality as a way of achieving power and control. So a generation of tribal people came home from boarding school with sexual abuse techniques because they'd been taught that—tribal people who experienced physical abuse, so they have a need to cope with their own powerlessness, and who have histories of sexual abuse so they can't protect their children.

These outside influences of learned behaviors (sexual and physical abuse) are subsequently acted out laterally within our own First Nation communities, as happened on the reserve in Canada, as happens in our political system yet today. We see the lateral expression and continuation of physical or sexual abuse in our Native families and communities. That is how the physical and sexual abuse, the political divisiveness, and the difficulties in collaborating socially with one another were introduced to Native people and perpetuated

in the tribal community. Of course, as a result, they perpetuate themselves.

We now have this generation of Natives from the federal Indian boarding school and the religious boarding school with their physical and sexual abuse experiences. This implies that tribal people in this generation experienced posttraumatic stress disorder in the boarding schools, following a childhood characterized by unregulated arousal, reactive attachment, and compromised behavioral immunity, and leading to an adulthood with higher incidence and prevalence of psychiatric disorders.

These Native boarding school era survivors raise and parent the next generation of tribal children with dysregulated arousal, reactive attachment, compromised behavioral immunity, anxiety, and depression (still within a crucible of ongoing postcolonial stress). Also, a further complicating factor has been introduced to the tribal communities: lateral violence becomes an issue in our Native community because tribal people bring this type of abusive tendency forward and act it out. This next generation of First Nations people goes forward with dysregulated arousal, reactive attachment, compromised behavioral immunity, and experiences of physical and sexual abuse. In the next section, we will examine the effects of overseas service and wartime posttraumatic stress disorder in the tribal communities.

Wartime PTSD, Tribal Termination, Neurodevelopment, Developmental Psychopathology, and Tribal People

Tribal people, as a subgroup, are the most decorated veterans of foreign war in this country. Native warriors have joined the U.S. military and have gone to overseas conflicts and fought in battles for the United States with great ferocity, with the greatest incidence of being rewarded for being heroic. Furthermore, there is evidence in the Congressional Record that a much higher percentage of Native and other minority soldiers was placed in the front lines in Vietnam (D. Walker, personal communication, June 27, 2002). Of course, these warriors come home with posttraumatic stress disorder to a cultural and historical experience of combined loss of language, loss of culture, loss of spirituality, introduction of sexual abuse, introduction of physical abuse, loss of community, and dispossession. Previously, we discussed the fact that their postcolonial childhood experiences within Native families in stress contributed to a higher potential of dysregulated arousal and compromised behavioral immunity. In turn, this predetermined a less than adaptive response to the war-induced posttraumatic stress experiences. In this case, our young Native war hero comes home to a terminated reservation.

Termination was a U.S. government experiment in managing the "Indian problem" by declaring that the reservation and tribal systems within which a given tribe lived or with which it was affiliated were null and void—that the tribe and all the tribal support systems no longer were recognized by the U.S. federal government and thus no longer existed (Ball, 1998). Passing a Congressional law that stated the tribe was so terminated preceded termination of a tribe. Subsequently, the tribal people's group holdings were "nationalized;" the Natives were given a few hundred dollars and told they're no longer Natives and their tribe no longer exists. These First Nations people were than exhorted to go about their business. In 1998, Ball examined the effects of termination with respect to causing posttraumatic stress among the members of one Native tribe. The effects of termination were carefully compared to other forms of posttraumatic stress disorder-inducing experiences that members of this tribe had experienced, including deaths of tribal members, violence by the police, and other historical postcolonial experiences. Following termination as a tribe, these tribal people provided test scores indicating a rate of posttraumatic stress disorder that was ten times that of the U.S. population at large.

As a result of tribal terminations, yet another source of tribal posttraumatic stress disorder exists. At this point, we have a generation with two more sources of posttraumatic stress disorder: overseas war service and tribal termination. Envision equal opportunity trauma to our hypothetical Native couple. He went to war and she went through a tribal termination experience. Alternately, she went to war and he went through a tribal termination experience. It matters little what the mechanism of induction was for the developmental insults; what is critical is that these developmental insults accrue in addition to the historical postcolonial stress and concurrent ongoing postcolonial stress effects on the family that forms when this couple marries.

Imagine yet another postcolonial stress-inducing effect at this time to our latest tribal family. This postcolonial stress-inducing experience is called relocation. Before they actually meet, this young couple is sent through the U.S. federal relocation project, as individuals from two different reservations, to the city. The relocation program is designed to help young tribal people assimilate into the western economy and culture, by transporting them to the city and providing a small of amount of money to live on as they become established. What happens is that as he returns from war and is given a bus ticket to the city, and some "seed money" to begin a new life, she leaves the reservation because, as a result of termination, she no longer has a tribal setting within which to live.

Relocation, Alcohol and Alcoholism, Neurodevelopment, Developmental Psychopathology, and Tribal People

Both of the hypothetical Native individuals go to Los Angeles or Minneapolis or Seattle or wherever; no one speaks their language, it is difficult to communicate, and they don't have the skills to interact adequately in the highly commercialized western economy and market. But, the young Native people meet, form a couple, and have a family in the city. Let's say they are now living in relocation in Los Angeles, a foreign country with respect to their history, beliefs, values, communication skills, etc.

What happens is that this young Native couple lives in poverty, due to lack of job skills and language skills and ongoing racism and oppression. What coping mechanism do they have in the city to deal with all of the internalized pain or to regulate arousal? Of course, beverage alcohol becomes the answer to internalized pain and dysregulated arousal. A generation of tribal people is now living in the cities and is using alcohol excessively to cope with their pain and unregulated arousal (postcolonial stress). This young Native couple continues to bring forward into their family interactions and to their children the physical abuse and the sexual abuse from lateral violence they have experienced, the trauma of termination, the trauma of war, the trauma of relocation, the cumulative effects of postcolonial stress. As a result, Native children of this generation have dysregulated arousal, reactive attachment, and compromised behavioral immunity as a basis to combine with whatever developmental insults occur to them.

Since there's beverage alcohol being used extensively in this generation of tribal people, as a result of cumulative postcolonial stress and internalized emotional pain, the first generation of Native adult children of alcoholics is created within their children. This underlies a further fragmenting of the psyches of tribal people. In addition, the first generation of Native people with alcohol-related neurological deficits secondary to maternal alcohol (and drug) abuse during pregnancy is born. Thus, another generation is created of Native people with dysregulated arousal, reactive attachment, compromised behavioral immunity, alcohol-related neurological effects, sexual abuse, physical abuse, and experience of complicated and subtle oppression. The dynamics of racism and oppression are becoming quite sophisticated, and as a result young tribal people begin

internalizing that process and identifying with it as a self-image.

Implications for Research with Contemporary Tribal Communities

What are the issues of this generation of tribal people? Gangs and gang membership, alcohol, drugs, and the biased dominant culture child protection services and adoption. It is this generation of tribal people who may have a child of four years of age who is reported into the child protective service system because the parents are substance abusing. Substance abuse and parenting skills are an issue. But, this young tribal family is carrying a lot of weight from the past in the form of postcolonial stress effects and concurrent ongoing oppression. These young Natives might be contending with a gang membership issue, where it is dangerous for them to withdraw from the gang, but legally they must in order to retain their child. Their ability to parent might be compromised by needing to participate in a demanding temporary aid to needy families (TANF) system, while simultaneously completing an outpatient substance abuse treatment program that was never designed for Natives and is not a culturally appropriate route to abstinence and sobriety. These are the issues of the current First Nation generation in the U.S.A.: poverty, substance abuse, psychiatric disorders, oppressive political and racial systems and agenda, culturally inappropriate child protection efforts and treatment methods, and the cumulative effects of several generations of postcolonial stress.

For purposes of this paper, in which I am reviewing papers on research and program evaluation methodology in the tribal community, what is the value of discussing postcolonial stress and the cumulative effects of postcolonial stress? Well, if we are conducting research in the tribal communities, this generation of Natives is the research subjects. These are the people on whom we conduct research. So if we're thinking about disability, we need to think about the relationship between disabilities and psychiatric disorders and stress.

I think when we start to examine these issues as researchers and begin to think about our research subjects, the postcolonial issues become clearer. Researchers step into a Native family that's already carrying quite a psychological burden and say, "Hey, trust me. Throw yourself open for research. Let me interview you. Let me give you this questionnaire. Oh, don't worry. It won't hurt. It's for your own good. I'm here to help you." I'm not implying that researchers are not looking to help Native people, but I am saying that the tribal people whom researchers want to examine and to help are psychologically and emotionally carrying a large amount of cumulative history and the effects of their history into the research. I think that in order to do ethical and moral research in the First Nations community, we must be aware of the postcolonial stress impact as an issue for the tribal research participants.

How does research impact the First Nations community and tribal research participants? I saw discussing and using the participatory action research model as an opportunity to create a research guide, a postcolonial participatory action research model, that addresses postcolonial stresses in a positive manner by engaging in research that is perceived as needed by the tribal community and endorsed by the tribal community. Integration of the participatory action research model makes tribal people full partners in any research attempt that involves them. This participatory process gives tribal people the opportunity to set the agenda of research that affects them. I'm suggesting researchers take a hard look at what tribal people want to study and how they want to study it. That brings me to the following brief discussion of postcolonial participatory action research as a method.

Practical Perspective: Postcolonial Participatory Action Research

Fisher & Ball (2002a, 2002b) described participatory action research or collaborative community research as an ongoing process of interaction between the researcher and research subjects. The team of researchers and study subjects alternately thinks about and modifies the research process as they conduct the research (Brydon-Miller, 1997; Lewin, 1946; McTaggart, 1991; Whyte, Greenwood, & Lazes, 1989). Scientific principles are the basis of this research approach, but care and attention are given to the values and beliefs of the community and the ongoing involvement of community members in formulating and conducting the inquiry (Fisher & Ball, 2002a & b); Greenwood & Levin, 1998; Greenwood, Whyte, & Harkavy, 1993; Park, 1999). Obviously, this participatory action model of research is very sensitive to tribal community needs and agendas as it fully involves the tribe. Furthermore, the tribal community sets the research agenda and selects and prioritizes the issues for investigation (Fisher & Ball 2002a, 2002b). As Fisher and Ball point out, the participatory action research model allows for examination of Native strengths, versus deficits, and emphasizes the use of Native knowledge (retraditionalization) to address current issues. Effective inclusion of tribal members as research participants and effective participatory action research require specific processes. It is beyond the scope of this paper to expand on these processes in depth, but I will briefly describe Fisher and Ball's recommendations regarding participatory action research in the tribal community.

How Participatory Action Research Works in the Tribal Community

Fisher and Ball (2002a, 2002b) recommended five principles for participatory action research in the tribal community, that emerged from their shared project with a Native tribal Head Start program, entitled the Indian Family Wellness project (IFW). First, the tribe must have oversight of the project, this oversight consisting of three components: 1) tribal council resolutions, 2) tribal oversight committees, and 3) the development and implementation of a tribal research code. Second, this model advocates the training and employment of tribal members as project staff. Third, a tribal facilitator acts as a liaison between the project staff and the tribally appointed oversight committee(s). Fourth, and of greatest importance, is the use of culturally specific interventions (derived from tribal beliefs and values, not adapted from elsewhere) as the experimental variable(s). Fifth, alternative research methodologies, such as the multiple baseline approach advocated by Biglan (1995), are helpful because of small sample size. And finally, sixth, the potentially negative effects of assessment instruments must be considered before any assessments are used.

In the next section, I will review the papers presented and discussed at the AIRPEM Symposium.

Discussion of Postcolonial and Participatory Action Research In First Nations Research and Evaluation Projects

None of the papers reviewed in this critique explicitly used the construct of postcolonial stress in the critique or discussion of the research or evaluation. However, it was evident that the authors of all the papers recognized implicitly that postcolonial stress was an important issue, which must be taken into account during evaluation or research. Also, although the authors differed in the depth and focus of the attention that they paid to the issue of participatory action research, each paper also contained good descriptions of various aspects of this research and evaluation process. Next, I discuss the reviewed papers with respect to the criteria developed in the coding instrument (see Appendix C). The coding instrument was used to analyze the integration and use of postcolonial stress theory and participatory action research in the theoretical papers discussed in the following section.

Findings and Discussion

Hillabrant provided a strong discussion of the type of sponsors who provide funding and support for research in Indian Country and the stakeholders affected by research in Indian country. He emphasized that sponsors of research in the tribal communities have increased their solicitation of input from tribal organizations and tribes. Furthermore, many tribes have actively pursued more active involvement in the evaluation that affects them. Hillabrant pointed out that there is increased tribal control of the research approval process and use of tribally operated or sanctioned institutional review boards in reaction to a history of exclusion and exploitation of tribal people through research (postcolonialism). He reported on and recommended five key research processes that tribes are or should be requiring or implementing: 1) hiring tribal members as research assistants and data collectors; 2) clearly describing the beneficial impacts of research findings for tribes and tribal members; 3) adequately guaranteeing that the tribe and environment are not harmed by the research protocol; 4) absolutely guaranteeing tribal, community, family, and individual confidentiality and anonymity; and 5) requiring review and approval by tribal representatives of all results and findings. Finally, Hillabrant presented several vignettes regarding the ethical issues and dilemmas in Native research and the various specific factors in tribal communities that exacerbate them: lack of cultural competence, poverty, illness, and deficits in infrastructure.

I was pleased with Hillabrant's solid description of the scientific history of research in tribal communities, and by his focus on and description of the five key processes currently being required by tribes and tribal organizations, which closely parallel the postcolonial participatory action research recommendations. Finally, I believe that Hillabrant's concern with ethical problems was appropriate and is needed as a further focus in future discussions of tribal research and evaluation.

Davis and Keemer provided an excellent historical perspective of the potentially destructive nature of research in tribal communities. Their paper clearly and graphically delineated and described post-colonialism in research at its worst in the tribal communities. Next, Davis and Keemer mentioned a detailed example of the violation of trust and exploitation of tribal communities, in their description of the misused and harmful Barrow alcohol study. I applauded the next section of their paper. They described and recommended participatory research, including community ownership of the research process, tribal approval and oversight, awareness and sensitivity to cultural issues, the establishment of a tribal research code (and example of a research policy statement), obligations of the researcher, and community control of data and results. An example of participatory action research and collaboration between tribal grandmothers and researchers provided a good practical example. Four research codes (three formal and one informal) were briefly described and references and web sites to locate these research codes were provided. Finally, Davis and Keemer concluded that tribal people have begun and will continue to demand that research involving their communities be collaborative and participatory in nature. Several recommendations were provided: study service utilization rates, closely protect information gathered by tribal members used in data collection, focus new research on tribal and community strengths as well as on the commonly examined deficits, be aware that there is a great need for careful research in the Native community as we know little about tribal people in contrast with other populations.

I enjoyed the excellent history of postcolonial research and the potentially negative effects described by Davis and Keemer. The example of the Barrow alcohol study and effects was appropriate. The most important section of this paper was the set of recommendations briefly listed above. Clearly, further clear

recommendations into the uses and areas for research in the tribal community must be developed and discussed in articles following this piece.

Marshall, Johnson, Kendall, Busby, Schacht, and Hill provided a clear rationale of the need for specifically trained researchers to study disabilities in tribal communities. They openly articulate the need for cultural perspectives and awareness when examining Native individuals, families, communities, and systems. Furthermore, research design and implementation must occur within a cultural context that necessarily shapes the evaluation process. Marshall et al. plainly described and openly advocated a participatory action research model with a specific focus on securing the input of disabled persons (Consumer Concerns Method). Culturally specific sampling procedures within the community and relying on the community were described. Tribal members were used as data collectors and a Native was trained as coordinator for research supervisory purposes. Instrument and question development for the study involved a collaborative advisory committee of both service providers and consumers.

It was evident that collaborative relationships were required for representative sampling. This required tribal members as key collaborators: liaisons, guides, instructors, facilitators, and even friends. Collaboration underlay the development of trust, the two-way facilitation of accurate communication, and recruitment of a representative sample of participants. One lucid example of collaboration in the Eastern Band of Cherokee was provided and the author discussed the beneficial impact of participatory research on his career. It is critical that further research is conducted on the issues of Deaf Natives and several of the challenges to this research were delineated. It was proposed that researchers working with tribal communities can learn from the experiences of researchers working with other aboriginal populations worldwide. One particular group of people, the Australian Aborigines, has achieved a very carefully constructed and comprehensive set of guidelines for research into their community that might serve as a model for First Nations in America. Finally, it was recommended that no research be conducted outside of a deep understanding of the cultural context.

I was impressed by the commitment of Marshall et al. to collaboration within a cultural context that is defined by the tribal participants. Their call for equal partnership was important. I think the most critical part of the message that I derived from this paper is that disabilities research must be based within a participatory action research model that recognizes racial culture. Further, it must equally be based in a collaboration that recognizes that disability creates a subculture and that both racial and disability culture must be taken into account. One can not examine disabled people of any race or culture without having disabled collaborators and without making the assessment process reflective of the culture related to the specific disability.

Running Wolf, Soler, Manteuffel, Sondheimer, Santiago, and Erickson began by recognizing that the research and "psychological" paradigm itself is a construct largely based in western worldview and assumptions and often has little meaning in the tribal worldview. One aspect of this disparity is that often the term disability has a radically different meaning to tribal people than it does to researchers or interventionists. Running Wolf et al. pointed out that initially an understanding of what a family represented in the tribal communities was needed. Each of the eight tribal communities discussed created its own specific program in collaboration with the technical assistance offered by the granting agency. The challenge for Running Wolf et al. was to assess the eight widely differing tribal Circle of Care grant-based programs in a manner that would demonstrate their individual effectiveness and outcomes. This assessment was supposed to be conducted using a specific set of instruments (clinical measures) that had little reliability and validity

in tribal communities. As a result, each of the tribal grant communities modified the data collection methods to most closely reflect their needs. Several alternative methods were created and the federal government adopted a flexibility plan based on these methods, which allowed for further instrument development or creative use of the current instruments. Of note was the use of two primary methods, community-based advisory committees and collaborative skill-building relationships between community and evaluation team.

This paper established that comprehensive and culturally competent evaluation in tribal communities requires tribal community leadership and collaboration. It became clear that tribal communities were effective at identifying needs, determining a course of action, and taking needed steps to achieve their goals. Finally, federal recognition of the need for flexibility and collaboration allows for greater participatory action evaluation and research in the grant-based tribal Circles of Care in the future.

Running Wolf et al. faced a tremendous challenge in collaborating with the tribal communities in implementation of the federally mandated assessment methods and instruments, and an equal challenge in working with the government on these issues. What I liked was that this team facilitated a collaborative effort with the tribal organizations and that they further advocated for federal change and flexibility. It is important not only that researchers and tribes work together, but also that researchers with relationships to research sponsors seek to facilitate a greater collaboration among themselves, the First Nations, and the research sponsors. I was pleased that Running Wolf et al. reported progress in this direction.

Summary

The use of the postcolonial stress model and terminology was not explicitly evident in any of the papers reviewed. However, awareness of postcolonial stress and the issues of postcolonialism was apparent in these papers. Of greater importance, perhaps, was the clear sense of need for a participatory action research model that emerged from these documents. Each of the authors recognized and discussed the importance of tribal control of the research agenda and activities in Native communities. The requirement for researchers and community members to collaborate and that community members hold the lead in setting the research agenda was evident. The importance of cultural understanding and the use of a strong cultural basis (far more than adaptation of other perspectives and methods that have worked elsewhere) for the research and interventions was evident. Several specific recommendations for the research process were provided by these authors that were reflective of those mentioned as important in postcolonial participatory action research and thus included as coding instrument criteria (Fisher and Ball, 2002a & b).

Some questions remain for further discussion:

- Are the postcolonial stress model and terminology valid for discussing research and evaluation?
- If so, is it helpful to integrate the postcolonial stress model and terminology into discussions of research and evaluation?
- Should further work be conducted on integrating the postcolonial stress model into the participatory action research model?
- Should efforts be made to integrate the postcolonial stress model into understanding the experiences of other aboriginal cultures: Australian Aborigines, New Zealand Maori, Canadian Natives, or South African Blacks, for example?
- Is postcolonial stress a factor in disability?
- Is participatory action research a "better practice" for tribal communities?

These questions and others similar will form the basis of understanding the relationship between the theories used as a frame of reference to understand American Indian Research and Program Evaluation

Methodology. I hope that a further and deeper exploration of these two related themes, postcolonial stress and participatory action research, and of the topic of research and program evaluation in tribal communities continues in the future.

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Ms. Holly Echo-Hawk: I really very much appreciate what you're saying and your reminding us again of the impact of postcolonial stress. Those terms seem so simple but the profoundness of what happens makes them such a huge understatement. . . . I'm thinking of the Sault Ste. Marie Chippewa in the U.P. [Upper Peninsula] of Michigan; their tribal council took a very hard stance, probably one of the most clear statements I've ever seen. They've seen programs come and go, researchers come and go, and at some point they decided that things were not getting better for their community. They came out with a tribal resolution that very clearly said—and I'm paraphrasing—"We're not doing anything else until we as a tribal community deal with and confront our historical and intergenerational trauma."

What they did is very similar to what you were talking about. They used a Canadian Native consulting group and stopped the music, so to speak, and put up a multiyear curriculum for their entire community. They have sessions facilitated by these Canadian Natives. They look at language, the impact of language. They went back and retold their tribal history from their tribal perspective, not from books, not from the history, but from their own tribal perspective. They had huge grief and loss ceremonies where their community people basically just cried. Some people say that until you can talk about something without crying about it, your pain and your trauma about what happened to your tribe and your family, you really can't do the work until you get past that phase. So they collectively put together this process to really grieve and to really bring that pain out on the table for their community. It is a very powerful process, and they're still involved in it. It started with the tribal council, starting from the top down, saying, "We are going to do this." And that's just one example.

The other example I was thinking about as you were talking is an Alaska example. I was out in the Bethel area last year and went to several of the villages to interview kids and families. The one that really struck me, that really makes this real, is Hooper Bay, Alaska. Hooper Bay, as you probably know, is out on the Bering Sea. Obviously you can only reach it by bush pilots flying you in, and you can hardly see the difference between the land and the sea in the winter because it's all frozen as far as you can go out. The only mode of transportation is snowmobiles, snow machines. There they had this huge epidemic of youth suicides. A very small community and very isolated, and very much impacted by the devastation of different kinds of organized religion coming into their community, historically, and lots of long, long trauma. Pretty serious gambling problems. The moms, the 30- to 40-year-old parents there, are very concerned and almost upset that their elders are really not elders, some of them told me, because they are drinking and gambling and they're not really in a place where they can be true elders.

So, lots of pain in all the different levels. But the thing that struck me the most is the suicides—the epidemic of suicides in this small village. In the winter time they cannot even bury the bodies. The caskets were stacking up outside because they can't bury the bodies until it thaws. If you can imagine the pain of these families, and the kids in the high school there, watching this huge epidemic of suicides—and the caskets are stacking up literally outside their windows. They can't even bury their dead until it thaws. It was just the most profound example, when talking to the kids and families, from little kids to teenagers to parents to grandparents, and to the police. I spent a lot of time with the tribal police there and other kinds of school people and system people. It was incredibly profound as an example of what you just demonstrated for us.

I think the eye opener, once again, for all of us around the table, is your point that this is the research population that [we] all work with. And the helicopter approach, which Jamie talked about, which she is not recommending, flying in and flying out, is not really giving folks the truth depth, the true picture of what those communities are about. I spent this time going to different villages, as you all probably did, but the Hooper Bay experience was the most profound.

One of the young men I talked to and interviewed was a high school student. Five of his friends in the village, teenagers, had committed suicide in the past year. His sister committed suicide and he found the body a couple of months before I was there. He had a very quiet, kind of typical Indian way of telling me his story and his pain. After I left and finished that series of interviews I was doing there in the villages, I came back with the decision that I would never do that again. I will never go into a community again and do interviews. I just won't do it, because I felt, personally, that I brought a little bit of excitement to that village because here I was, a stranger person coming in, and Indian of some type, maybe not Alaska Native, so I was treated very well and people were kind to me. But I felt like no matter what the cause was for that research, I won't do it again. I will never go into a community that's in so much pain. That was such a profound example, because there was so much pain and I came in and brought a little bit of excitement, in the sense that here's this stranger person walking around. But I left feeling terrible because of what I had done. I went in and had to have people tell [their] stories and open up some pain again. I couldn't offer any help and I left. So my personal experience that I want to share with you is that I will never do that again. It was not fair to that community. They needed some help right away and I wasn't there to do that. All I did was go in, open up some wounds, and leave. It made me personally feel bad to do that and to do that with the best intent of doing a job, but it made me feel bad. It still makes me feel bad. So that's the end of my story that I wanted to share with you.

Dr. Jamie Davis: I think it's important in our communities, and probably for science, to do things, not necessarily that we all agree with and have support for, but that include some sort of historical or theoretical analysis. As I was listening to what you were saying, Joe, which I really appreciate, I think to move it even a bit farther. Among Indian people there is an increased arousal which may predispose us to needing some additional arousal, seeking some sort of arousal that may lead to potentially greater interactions with risky situations. And then that might lead to an increased chance for physical disability—if you need increased arousal and you run across a busy highway you might get hit. So I think this isn't necessarily just about the psychological impact of these things. It's also about how postcolonial stress could impact on communities resulting in additional physical disabilities.

And I think, along that same line, of dispossession. We're feeling dispossessed, a lack of sense of self, of who we are, or, as some psychologists might say, a lack of ego or a good grounding in who we are. We don't have as much sense of respect for ourselves if we don't really know who we are. And if we believe that we have no value because we're believing, after so much repeated abuse and war and negative treatment, that nobody else is valuing us so why should we value ourselves, again, I think that could lead to people being less careful and taking greater risks.

So now [perhaps] we can add yet another level, drinking and driving, not caring for our children, leaving them in a situation that could be risky or dangerous, and again increased accidents, increased physical disabilities.

And where my thoughts went from there was again to the increased alcohol use. I'm really trying to get a little bit to a genetic level or to a neurotransmitter level, which is where my line of reasoning probably stuck because I am certainly by no means a physiologist. But we

know that there's certainly a relationship between FAS [Fetal Alcohol Syndrome] and FAE [Fetal Alcohol Effects]. We certainly know not only the increased impulsivity and emotional issues that go with FAS and FAE, and some of the other prenatal issues that could potentially lead to ADHD [Attention-Deficit/Hyperactivity Disorder], and some of the family issues that could lead to some of these—but FAS and FAE being more of a chromosomal phenomenon.

Now, where I really wanted to go was to ask if there was any sort of decreased physiologic immunity that could be related at any level to increased risk for any sort of genetic disabilities. And I don't think we can probably make that argument. Again, I'm not a physiologist, but I thought it was interesting to consider if we had a compromised behavioral immunity, because I do think that's a very powerful way of looking at things. Is there any sort of compromised physiologic immunity? I doubt that that will be the case. But it is quite exciting and quite stimulating just to be able to let one's mind think about all of the implications for disabilities, and the impact of history and treatment, and where we now need to go—full circle back in our research, to understand the impact of postcolonial stress and multigenerational stress, to inform and direct our research.

I was also really touched with [what the Sault Ste. Marie community did.] I believe when I was up in Sault Ste. Marie they were talking about this, but it was almost two years ago; I was new and not remembering everything—but to remember that they have made this tribal resolution, and that it's important in looking even in my own life, which many of us can probably do, and the impact of not speaking, not being allowed to speak, the tribal language of my parents. My grandparents were not allowed; my grandmother was not allowed. My father doesn't speak a whole lot, my mother doesn't, because they were trying to fit in and be acculturated in the city and not be discriminated against.

Dr. Walter Hillabrant: I think what we're talking about—I like the way that you phrased it—is looking at the construct of postcolonial stress to inform our research in general and these papers in particular. And to that I have two comments.

The first is yes. Yes, yes, yes. If by that we mean, for example, that what we do and how we live and where we are is done in a matrix that involves the historical context of our ancestors, it seems to me that it's shocking that people would ignore that, but it happens all the time—and I'm glad that Joe brought it up.

In my own paper I would say that where I approach that is with respect to the issue of ethics that I talked about yesterday and the day before, which is to say I believe it's unethical for a researcher to present findings in a vacuum, without pointing out the current context, the social and political context, in which the research occurs—and you can't point to the current social, political, and cultural context without paying attention to constructs like postcolonial stress. It's fundamental and it's right. That's my first point.

As I get older and older, I think we need to be brave and I think we need to be strong and I think we need to be smart. And in saying so I am very sensitive to a couple of other issues. One of which is that as my life goes on, I tend to see things as being variegated. Almost everything has both rewards and costs associated with it, and all too often we as researchers and individuals focus on either the rewards or the costs, depending on our political, economic, cultural interests and aspirations. And as social scientists, in general, and psychologists, in particular, I think we have a terrible checkered history of jumping on band wagons, focusing on *either* rewards *or* costs. At one time it was psychoanalysis; it was our true religion, you know. And after we went through psychoanalysis, there were other things. If you wanted to make a joke of it you would say things like primal scream or whatever. So people will get a construct and they will ride it into the ground.

And so I have—if I'll be honest about it—a kind of negative reaction to your matrix, which as I see it is a Procrustean bed: "I've got a construct and now I'm going to filter the world through that." I don't think there's anything the matter with doing that; I think it's probably good. But as a person who is sensitive to being brave and honest there's a couple of—I don't want to call them costs—but limits, that I think are worth thinking about. One of them is that I'm always wary of constructs and theories and propositions which aren't testable, so I think it's really important, when people have a construct, that they be able to point to incidences and situations where they say, "If this, that, and the other thing were to occur I would be wrong or I would have to change the nature of my construct." So I challenge people who want to explain lots of things—I don't think it's fair to say everything, but people who want to explain lots of things—in terms of postcolonial stress, that they be able to articulate areas of discourse that would be inconsistent with that. That's one general proposition.

As researchers, if we're going to go into this issue, we have to address some things that are really tough to deal with. One of them is that there are other populations that have been subjected to postcolonial stress. There is a remarkable article by Daniel Goldhagen in a recent issue of the *New Republic* (Goldhagen, 2002), reviewing the history of anti-Semitism in Europe. Most of us know a lot of that history. Some of us probably know that in 1492 the Jews were expelled from Spain by Ferdinand and Isabella, and that gave rise to the Sephardic Jews. But I bet a lot of people here don't know that after World War II, in 1946, the Poles killed over 1,000 Jews, that pogroms and ghettos existed in Europe starting around 700, and that the Crusaders as they marched their way to the Holy Land would stop off and kill Jews.

It's unbelievable what that history is, so to the degree that postcolonial stress and genocide and those constructs have merit in Indian country, they ought to be applied to some other cultures to look at the cultural components with respect to that construct.

I think another thing that we need to struggle with when we look at our communities and those explanatory concepts, if we're looking at multigenerational effects of systematic deprivation, which it is undeniable that our communities have suffered, another thing that we need to look at is strengths in our communities.

We have unbelievable, remarkable situations of strengths in our communities. I'm reminded of a study that we did on family violence; the communities insisted that we say it's a study of family violence and community strengths. So, how is it that the majority of the people in Indian Country don't drink and abuse liquor, that the majority of people in Indian Country don't abuse their kids sexually or physically? How is it that we have those strengths, and how can we tease apart the strengths from the residual effects of the postcolonial stress in the systematic genocidal things our communities have been subjected to?

I want to conclude by saying I celebrate the strength of Joe and other people who are willing to look at this issue and to keep it in our consciousness. I think that's good. And for that I thank you.

Dr. Paulette Running Wolf: Where do I follow with all of that? First of all, I want to say thank you, Joe. I think you did a remarkable job of framing and bringing to the table the history that we need to keep in mind, and I very much appreciate your challenge in terms of trying to structure what we're doing and our agenda in terms of postcolonial stress as well as within a participatory research model.

What I'm personally struggling with, as in Holly's story and the stories Joe shared, is whenever you talk about the pain in Indian Country, most people can reflect back on their own history and the pain. You know, I just kept hearing my grandma saying, "I could never hug my kids." I said, "Why, grandma? What do you mean you could never hug your kids?"

She said, "Because I thought I had TB, and if you had TB you were taken away and put in an institution and you were never seen again." So, you know, I remember. And that was just *my* grandmother. And all of those issues of language and culture and ceremony and traditions that are passed on. I think what's really remarkable is that we still have them. It's just amazing that we still have them. I think that's testimony to the strengths, and so I appreciate Walter's comment to keep in mind that Indian communities have this remarkable strength, this perseverance, this resilience—that we don't really know what that is all about and why that is, but it's there. It's there without a doubt, you know. In every Indian community that I have been in, too, I am struck by the core that's there. That core belief. That core aura of identity, Indian identity.

I'm also struck by how all of the tribal communities that I've been working with through the CMHS [Center for Mental Health Services] process are talking about historical, intergenerational trauma. How do we maintain our culture in light of disability, in light of these weaknesses, these vulnerabilities, this pain that our parents, our communities are experiencing? They are all talking about that and looking at that, and they're all so strongly invested in their culture and in their identity.

I think about the communities that are developing their own research instruments, that are proceeding with taking charge of the research agenda that's in their communities and saying, "No, Macro, we do not want a non-Indian coming into our community and asking questions. We have some people of our own who can do that and who can frame it in a culturally relevant and appropriate manner—and then, as a result, very possibly deal with some of the pain that those very questions may be asking."

I'm struck by the parallel of the experience that's going on in Indian communities, in terms of interventions, therapy, handicapping, treatment, and all of those things, and what we're talking about here today as researchers—because we're still struggling with those same issues. I don't know that there's one answer. But I do know that we are missing some voices here. I'm thinking we're missing elders here. I'm thinking we're missing some kids here. I'm thinking that we're missing some of our elders in research country; it was great having Spero here, but there are also Theresa LaFromboise, Joe Trimble, John Red Horse.

And lastly, I just want to acknowledge the need to keep in mind that history, to carry that history with us. It has been—as Joe has so eloquently pointed out—that that history of pain is deeply seated, and the strengths are there as well, and so we need to keep both on the table.

Dr. Catherine Marshall: Dr. Stone, your comments brought up what for me was a very traumatic experience. About 10 years ago the American Indian Rehabilitation Research and Training Center in Flagstaff used to have a counterpart, the Pacific Basin Rehabilitation Research and Training Center, which was based in Honolulu and later in San Diego. I had suggested that we pull together those two RTCs to look at what we knew about indigenous people and disability through those two rehab research and training centers. From the '70s there had been some very good articles written about how crazy it was to go to Saipan (which I'm sure you all know is a trust territory of the United States due to its strategic location near Japan in World War II). We would go to Saipan and Guam and say, "Let's talk vocational rehabilitation and what jobs you are going to get here in terms of gainful employment, 8-5, 40 hours a week." Some rehab folks back in the '70s were writing about how ridiculous that was and saying that maybe we could look at other ways of successfully defining what is a successful vocational rehabilitation. Well, that idea of researchers from those two centers getting together became a three-day symposium—and it quickly deteriorated into non-Indian versus Indian at the table. For three days we talked about how horrible it was for non-Indians to be

involved in rehab research. For three days, I was clearly the enemy—and I left there very traumatized but with a phrase that goes with me everywhere I go, every day, 40 hours a week, a phrase that a Maori physician gave me: "Every time you walk in any door as a researcher, remember that you carry 200 years of history with you." I've done that, and I tell you it requires nerves of steel to walk into a room of Indian people and say, "I'm here to do research." And then you wonder why you do it, and that gets into the whole question of whether research should be by Indians only. I heard that message of the 200 years of history I brought with me, but I never until your presentation thought about how these are the people whom I'm giving a survey to or interviewing and saying, in my standard approach, "What needs do you have and how can rehab help?" When we say, "I sent out 500 surveys and I got 7 back"—not that I would do that, but as an example—we'd think it ludicrous, as in the situation of sending an Indian person with a disability, quadriplegia or whatever, a 10-15-20 page survey and saying, "Please document your needs, mail it back and we'll see what we can do in terms of rehabilitation and employment."

I really think that better understanding and thinking about who I am really asking to respond to these questions is very good. And yet, I've heard just some tremendous stories—one, of a brother who is severely brain injured from a car accident. It turns out that in 20 years you're the very first person ever to ask that family what they need and you truly believe you can make a difference, and, in fact, maybe in some cases you really have. It's amazing to me to think that it took a non-Indian researcher from Arizona to go to the Eastern Band of Cherokee and ask this man what he needed in terms of better helping his brother with a brain injury, and he sobbed so hard and so long that the secretary who was transcribing that tape said that she had to stop, and he said, "Thank you, because nobody has ever asked. I had no idea, since my brother was 16 years old and I was 15, and now I'm 35, what I could ever do to help him."

So, in terms of some disabling conditions I'm convinced that better understanding these and making sure that when federal, public, and state dollars are involved those folks and their families are adequately served is really critical.

However, back to your coding form, which is a real gift, I think. Regarding demographics, I think you should spell it out. What are we talking about here—Indian, non-Indian? Because in Indian Country race and color are critical, and I think that if authorship does not reflect the Indian contribution in these [papers], it has to. So if there's a blank under "Indian" on demographics it has got to be repaired, because we can't be talking about doing research in Indian Country when Indian contributors are not a part of the written product. So I think that's helpful but put out there what we already know: that demographics count in Indian Country.

Dr. Howard Busby: I do see some parallels with the American Indian research and the Deaf community research in talking about history. First, let me say that most Deaf American Indians are faced with trying to develop an identity that originates from four cultures. For example, there's 1) the culture of the *hearing majority and the environment, the white culture,* because they tend to go to schools that are located in that culture—and in talking about residential boarding schools, we have that same exact history within the Deaf community, where children are taken out of the community, put in a residential program, and historically we're not permitted to use our native language, which is an American sign language, or, for Deaf Indians, their tribal sign languages. They were forced to speak and lip-read. Our sign languages were rejected and the only way we were able to maintain them was to hide them outside of the classroom, in the rest rooms, in the woods, out of sight of the majority...and that was our lives. So I saw that parallel with the history that you talked about in the boarding schools. 2) The second culture that they're originating from is *hearing Indian culture,* which again they don't get a lot of. They may sense it, they may experience it and

the stresses of it from their families, but it's not in their language. They come from a visual environment. They perceive things visually; they perceive body language. Even if Deaf Indians cannot talk about or convey in *spoken* language their impressions or understanding of tribal or traditional lore, culture, powwows, prayers, etc, they still can do it in their own "inner" language, albeit at times erroneously. In other words, they do have interpretations of what is happening—we do have some structured concepts of what is happening in our tribes, but those concepts may come out mistranslated. 3) Thirdly, in relation to the *Deaf majority culture* that they end up joining after they leave schools or after they leave the reservations, they have to come up with some sort of identity to exist there, as well. 4) Then they find that there are also more *Deaf Indians in urban areas*, and they may form an organization like the Inter-Tribal Deaf Council (which is just now 10 years old), but they're still struggling with the development of that identity. So when you talked about the wars between the different tribes, we have that same thing going on within the Deaf community, because we also come from all different tribes and all these different concepts, and we're trying to develop some sort of tradition that we don't have—because whose tradition are we going to incorporate into our organizations? The Cheyenne, the western, the Seneca, the eastern—which of the parts are we going to bring together?

The last thing that I wanted to mention is the idea of resiliency. I believe that one of the things that has helped us to continue is resiliency. What is that? What's involved with that? Why are we so resilient? I believe there's something there. Walter, I believe, mentioned strengths, and I think that's part of resiliency and how it's able to maintain, because even though we have these negative factors and experiences happening, we have always had this resiliency. It has helped us to survive, and that's part of our strengths and we need to keep reinforcing that aspect. Sometimes parents, even though they have these postcolonial stressors, will reinforce still some of those resiliencies in their children, and that's how their children are able to survive. Again, as Walter said, this happens not only in our culture but also in other cultures. The same thing with Black culture; you see a lot of resiliency in their community. So I think, when we look at postcolonial stress disorder and PAR, we need to put in the element of resiliency somewhere, and I think that's how we define Deaf people's survival.

Mr. Calvin Hill: I believe that one of the symptoms that our tribe displayed down through history is evident in the research that we participated in 10 years ago. One stumbling block was that a lot of times researchers just pop in and do the research and then they're gone, and the tribe has no knowledge of what the outcomes or findings were, and that's why they were pretty hesitant about granting permission to researchers. I think they had a concern about what their findings were because no recommendations were made.

Dr. Catherine Marshall: Speaking about resiliency and trust, I'm always amazed that people do end up trusting and saying, "Yes, disability is an issue" or "Disability we haven't looked at and let's do it." And when you say, "I am the PI [principal investigator] and you will get the research reports back," you just have to do that, I think—but the history is definitely against you.

Ms. Holly Echo-Hawk: You're making a very good point, that given all of the history, given everything that's happened to tribal people, they will for the most part be kind, respond, be willing to give. It makes Indian people the greatest human beings, but it also makes them very vulnerable to the researchers being extremely vigilant about what they're doing and what they're taking.

Ms. Sharon Johnson: I find this whole conversation fascinating. I really appreciated that you included the boarding school experiences in the speech that you gave. That has always been an interesting topic. In

Minnesota we have a whole generation of people who were taught the shame and hiding, all of that. We lost the language on the reservations, and now it is more academic than anything. It isn't commonly used in homes anymore, which is a sad thing.

I really was interested in hearing Paulette talk about her grandmother. We think of historical diseases such as measles and small pox, and speak of them historically, and to some extent we do the same thing with tuberculosis, as she mentioned with her grandmother, but I don't think anybody realizes what a prevalent problem and what a continuous problem it was. All of the sanitariums in northern Minnesota were named with Indian names—Ah-Gwa-Ching, Nopeming—a number of them. People were taken for two and three years and they were just housed there and their children were put in foster care and farmed out.

Dr. Walter Hillabrant: I want to follow up something that Calvin was saying. In recent years we have slavishly returned results of our research to the tribes or the relevant portions of tribes, but I don't think that's enough. Typically what happens is that we'll send a draft report, somebody will say, "Yes, it's okay" or make some changes on it, we do that, and then the report is released. I think what's needed is the next step. It makes sense for the researcher then to come back not only with the report but—and this then gets into that applied research issue—we ought to come back and talk to people, kind of like what we're doing here. I'm learning a lot; we're exchanging—"Now, how does this relate to you? How are you going to use this?" Sometimes I think we bring a value as an outsider, you know.

Dr. Paulette Running Wolf: One thing that I think that needs to be in that model, Joe, is the whole history preceding the Indian Child Welfare Act and the removal of children. I think that we tend to think about that as a landmark piece of legislation that really impacted Indian country. Well, it put the issue on the table for a little period of time, but I don't think people have a real understanding of the depth of that issue in terms of the impact on our communities. Thousands upon thousands of children removed. For the Blackfeet alone, it was something like 6,000 kids removed. They were the most removed kids out there. What happened to those kids? And think about the intergenerational impact on those kids. That needs to be in the model. Secondly, I think we need to think about today and the issues that are impacting Indian Country today, because today it's just as present as yesterday. Indian kids are still being removed. I think the idea is that that stopped. No, it didn't stop. It did not stop at all.

Dr. Robert Schacht: In talking about the research implications, one of them is that you get the permission of the community to publish the report, or something like that. In an urban community, who would be the responsible body to give that approval? I don't know. And if there were two or three competing bodies, would they ever agree on a common result? And so what would be the appropriate procedures in that sort of situation, where you have a fragmented Indian community or one that is very diverse?

Ms. Holly Echo-Hawk: Yes, I think you're speaking to the diversity issue, in terms of a diverse group of tribal folks and the permission-gathering piece.

Ms. Kelly Keemer: I just want to say thank you to everyone for your comments this morning. I'm really grateful that I was able to help Jamie write this paper and to be here today.

I just want to stress the importance of looking towards the past so that it may provide us direction to move towards the future. I think that that's a very key point and I think all of us have said that today; everyone has recognized that. And I think that in doing research we need to recognize both the positive and negative, and that's also what people have been saying—that we need to realize our past history and that things haven't always been good, but we need to look at the positive

things. We need to look at our culture, our traditions, our language, our communities that we still have. Those are very strong things that we still have and that we should be grateful for. And as far as the historical trauma, we also need to look at that as a strength, because even though there are 550 different tribes, all tribes have experienced the same types of historical trauma, and I think that can also bring us together.

Another question is why are we conducting this research? I think that we do research to learn more about the communities and the needs of the communities. In our paper I did the part on the participatory action research. I think that applied research is very important; with the results that we find we need to go back into the communities and through education help them, whether it's with diabetes or whatever the issue [is]. The other thing is that in my community I see that a lot of our community members' energy goes to the kids who are problem kids, who have behavior problems. In the news it's all negative; everything that is portrayed is negative. And even in our community I saw a lot of the energy going towards the kids who had problems, whereas the kids who were doing good stuff were not praised as much as they should have been, and I think that's very important.

Dr. Elizabeth Kendall: One of the layers of trauma in Joe's model should have been research because, in fact, in Australia, and I'm assuming it's the same here, research has been the vehicle by which many of those negative things have happened. I think that what's really nice, in relation to the historical traumas that Joe talked about, is that this whole monograph is offering a way that research can then be the healing for that as well, and I think that's a really positive thing. In Australia, for the last 15 years we've tried to put together some guidelines about research in indigenous communities; to some extent they are still a little bit toothless and they're on paper only, but the ideas are there. And I think that there's some use in those documents that we've developed in Australia, which is part of the reason why Catherine invited me to come here. I'm not saying we've got it right yet by any means, and we've certainly got a whole lot of other things really wrong, but in terms of research I think there's a huge effort at the moment in Australia to do exactly what this monograph is doing. To some extent it's working—because it's linked with funding for research. So unless you can document that you've met all these criteria you cannot get funding for your research in Australia, which is a really positive thing. I'm hoping that each year it gets updated, each year the criteria get a bit more stringent, and I'm hoping that eventually we'll reach a phase where PAR is the only methodology that's really supported.

Ms. Priscilla Sanderson: When I listened to Joe's presentation this morning, I was thinking to myself that the eastern tribes experienced acculturation first and so now the southwestern tribes are kind of checking out how they're dealing with the trauma, the postcolonial trauma. And I think you can see that we're not doing well in the southwestern tribes. I think we recognize the fact that we are losing our language and so we're trying to reach out to funding sources from the Department of Education and so forth and saying, "Help us so we can retain our language, so that we can be able to tell traditional stories to our next generation."

If you look at a grassroots level, when researchers come in there's expectation that something positive will happen, that there will be a change. I think that sometimes researchers don't realize that when they go into an Indian community at a grassroots level and start doing the interviewing, that they carry with them a history; that needs to be recognized.

Now, the dissemination aspect is capacity building, to me. Rather than just disseminating research results and writing a nice report, I think researchers should look at the community and say, "How can that community build capacity?" I'm not just going

to give you a report and walk away. How can I build capacity, how can I provide the resources? I think researchers who are going into the community should be cognizant of all the resources in the community as well as how they can assist in terms of providing information to the policy makers, such as the tribal presidents. I think there should be a presence not just at the time when the data is being gathered but afterwards, like when there's a tribal election going on. I think researchers should be there in front of the people and saying to the tribal presidents, "Look, this is what I found in your community. You're running for office. What are you going to do about it?"

Ms. Holly Echo-Hawk: You're bringing up how important it is to educate the tribal council, the powers that be in the tribal communities, about the research findings. General community meetings serve a purpose that's good, but the people who can make change are the elected officials—and how often that has to be done depends because of the turnover.

Dr. Velma Mason: I think we need to not overlook the tribal culture diversity and research diversity. We're talking about 563 federally recognized tribes and Alaska villages, plus state-recognized tribes. So when we talk about postcolonial stress we need to remind ourselves that there is this diversity and there are many tribes who have, I think, already dealt with it . . . Because we are so diverse there are still not only within-tribe differences but I think there are different ways. I have observed this postcolonial stress syndrome with a lot of young people. When I did my own research in 1974 I was director for the National Indian Drug Abuse Study. We tested some 4,000 subjects and in that experience I saw that there were a lot of young people with some really obvious identity problems, because of the intergenerational experience, lack of cultural transmission . . . I think there are a lot of us who may be in denial or who don't want to admit it because it is so horrible, so horrific, that this is done to Native American populations. And I think those people who are in that stage need to own up to it and deal with it, because people do become defensive about it, and so long as you don't deal with it I think Indian people see through that, and they will not accept you—because it's so blaringly transparent, you know, when people come to the Indian table with that defensive mechanism about them. So we do need to deal with it.

Now, somebody talked about the positive strengths with Native American people. I think there are some tribes that do have substantially very well structured cultural protective factors and so they do focus on the risk factors. Unfortunately, many tribes that have gone through some considerable acculturation process don't have that linguistic background, but [language] is a teaching tool that has actually helped them to understand their own behaviors, their problem behaviors, cultural values. A lot of the stories that are told, legends, origin stories, you know, they're told in the Native American language; I'm sure Navajo probably has the same experience. And some of those stories have a lot to do with the development of the moral philosophy or the ethics of man. A lot of that is actually contained in those stories. And, fortunately, many of the tribes that still retain their language are able to transmit that knowledge to their young people. So I'd conclude by saying that I think there are still many tribes within this diversity that still do have some really strong cultural protective factors. In terms of looking at best practices, I would encourage researchers to continue to look at that.

Dr. Joseph Stone: I appreciate the discussion. I'm glad that it took the directions that it has taken. What I'd like to think about with respect to the model is that the postcolonial piece is a bipolar piece. In a longer presentation we do deal with resiliency factors, and that's probably 50% of the time I spend with the presentation. And usually we spend the evening and the next day in talking about healing, which I think is real important for

activating those factors—and they are there. They are there in the community. Phil Lane came, many years ago now, to Montana, to Flathead; they brought him down several times from Canada to answer very complex questions about alcoholism and Salish Kootenai—and he always would be very civil and stand up and say, "The problems are in the community. The solutions are in the community." And they wouldn't hear that piece because they thought Phil had the solutions. And he'd go back to Canada and then they'd call him up again and he'd come back and he'd say, "The problems are in the community. The solutions are in the community." Finally they got it. Took one of their own and developed their own healing process there at Salish Kootenai based on the tribal belief system, the values. And that's participatory research. So in the model we do have the postcolonial theory, but we also have running in parallel with it the resiliency or strengths of the tribal communities. And what I see the role of participatory action research being is that very example of how Phil dealt with his consultations at Salish Kootenai: that the problems are in the communities and also the solutions are in the communities. And how participatory action research can work well is that it can activate the resiliencies or strengths of the community through applied research. Thus, as we drop out of the seventh generation or the effects of trauma and the presence of resiliency in abeyance of that trauma, when we come to the point we're at today, of professionals working within and from outside the tribal culture to help, I think what we see is an opportunity to lay the groundwork for intergenerational change. I like that notion of change, intergenerational strengthening, the activation of the resiliency, and, in parallel, the respect for and continued acknowledgement of the history that we bring to the table. Carl Jung always said, "I would rather be whole and have my shadow than be good, and a lot of my shadow comes from this history that I carry inside myself." And so, I think that as tribal people I would rather we be whole than good—that we have our history, we have our shadow—we have to grow.

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Focus on Implications for Policy and Practice

Velma Garcia Mason, Ph.D.

Good afternoon. I work for the Assistant Secretary of Indian Affairs at the Department of the Interior as the director for the Office of Alcohol and Substance Abuse Prevention. When I heard about this symposium I felt very optimistic to think that there actually are researchers interested in looking at Indian research issues. We (Indians who work on policy in federal programs) have been trying to obtain more knowledge on this subject so we could develop better policies and set some new directions on how the federal government should be responding to various issues, particularly with regard to alcohol and substance abuse and, from our interest perspective, disabilities resulting from alcohol and substance abuse.

When I looked at the papers, I asked myself four questions. First, "What is the value of this paper from the perspective of policy development implications at the local tribal level?" I have to entertain this issue because our policy mandate is to involve the tribal government in critical policy-making decisions as much as possible, and the federal government in the Department of the Interior is committed to honor and work with tribes within the framework of meeting their self-determination goals.

Second, I asked, "What is the value of this paper for policy development purposes at the federal government level?" The Office of Alcohol and Substance Abuse Prevention has a Congressional mandate, Public Law 99-570 (also called the Indian Alcohol and Substance Abuse Treatment and Prevention Act of 1986), to address the alcohol and substance abuse prevention needs in Indian Country, to provide needed direction and guidance to federal agencies responsible for Indian programs that address alcohol and substance abuse, and to focus existing programs and resources upon this problem (26 USCA 2402). When we look at research findings, we look at them in terms of how they would benefit tribes.

My third question had to do with the issue of applied research. Since we have a mandate to serve Native American populations, I looked at the papers in terms of their applied research value—i.e., "How can the federal government use the research findings, methodologies, and tools? How can the findings be used to help the federal government respond to the problem of alcohol and substance abuse, and how can tribes benefit from the research data at the program level?"

The last question was, "To what extent can the research findings be applied or incorporated into a response plan to the training needs of Native American populations at the tribal level—i.e., how can this paper help in transmitting knowledge and new technology to tribes?" So that is the perspective I used in my review of the papers.

As I'm sitting here over the last two days, I have heard a lot of similar concerns and points discussed, so I'm not going to spend a lot of additional time on them.

I was impressed with all your papers. I had an opportunity to conduct some postdoctoral research on a small National Science Foundation grant to develop some cross-tribal testing instruments and their properties in a partnership agreement with Johns Hopkins University and UCLA. That experience convinced me of the need to look closer at field research issues and the need to start developing more research capabilities within tribes.

Prior to that, I had also had similar experience working with field research issues on an epidemiological research project at Colorado State University, where we had received a grant to conduct a national study on Indian alcohol and substance use among close to 14,000 subjects. We were successful in obtaining a large sample of cross-tribal youth, from the Seminole in Florida, Apache Tribes in Arizona and New Mexico, Assiniboin Sioux at Fort Peck, Montana, Red Lake Chippewa, Navajo and Pueblo tribes in New Mexico. We were most successful because we worked with tribal councils to get their approvals and support for the project. We went into the school systems and worked with the superintendents and school principals to collect the data. From this research experience, I saw the needs that exist and I think you all touched on these issues in your papers.

Regarding Dr. Jamie Davis' paper, *A Brief History of and Future Considerations for Research in American Indian and Alaska Native Communities*, I agree in principle that in order for the tribes to trust the applied value of data, they must trust the researchers and the research institutes, which in most cases, are universities. I'm not sure they do have this trust, and as we have all said, it has been the practice that many researchers come onto the reservation, thank the people after they complete the data collection, and leave the community with no further sense of obligation to the community. That is the impression that Indian communities have of researchers on reservations. So Jamie hit the nail on the head when she said that historically, because of that experience of exploitation of Indian people, a lot of Native Americans are reluctant to work with researchers, especially non-Indian researchers. Actually, they probably distrust Native American researchers who do that as well.

What's missing from the paper, in my opinion, is the value of some of the previous research by American Indian researchers; for example, Dr. Bea Medicine's work and that of Dr. Edward Dozier and Dr. Alfonso Ortiz were among the early pioneering work in Indian research. I am sure there are others, such as Mr. Leonard Pinto, who conducted some valuable early research on alcohol and substance abuse among his people (Pinto, 1973). There was also some valuable work done in the '50s and '60s in the field of Indian education that was based on sound methodology acceptable to Indian populations. I believe that work, in fact, made a difference in setting a new direction for Indian education policy. It laid the foundation for many of us who came behind and tried to conduct similar research. One example is the Kennedy Subcommittee study on Indian education (Special Subcommittee on Indian Education of the Committee of Labor and Public Welfare, 1969), which was an enormously expensive study led by University of Chicago. This study was most successful because it trained Indian parents and incorporated participatory research in the community studies strategy. The study also incorporated qualitative research methods to supplement the quantitative data collection. In my opinion, the most valuable data came from the interviews conducted by the Indian researchers; as a result, many Indian communities were able to identify with the results of that study. The data resulted in the creation of the Indian Self-Determination and Education Assistance Act of 1975. This is a good example of applied Indian research.

In my own previous experience in quantitative research on Indian alcohol and substance abuse, I had the opportunity to examine its relationship to certain cultural and linguistic variables. These were very specific factors that were actually included in the instrumentation I had developed at the request of tribes that were participants in the research project. This protocol required the researchers to take a few steps backward and do quite a bit of item analysis with tribes so that the instruments used in the research to collect data would be useful to the tribes after exiting the Indian community. That research, in my opinion, was useful because it focused on defining the emic (Native) culturally acquired perceptions and/or

definitions of the variables, for example in my research on Indian identity, and some of you discussed that topic in your papers.

Dr. Spero Manson pointed out the tension between science and advocacy. I was trying to think how I would apply that to my own experience, and I think that it was an issue for me in my own research experience and it is still an issue today. It's not necessarily the science that's an issue, or even advocacy. I think it's the conflicting goals of scientific research and the commitment to applicability: knowing that the knowledge collected would address some of the local needs of tribes on reservations and being unable to take that step for a variety of reasons. The goals of science and advocacy are unfortunately totally different. It is rare that the same person can do both well, and that to me is the dilemma.

What I would like to pose to you is this question: To what extent is genuine collaboration or integration possible with these conflicting roles and goals? In my past experiences at various universities, it was my observation that "if you don't publish, you perish." So the conflict that Dr. Joseph Stone addressed yesterday is a reality for Native American researchers. When you are perceived as a researcher, you have to make a decision as to whether you would prioritize pure research or work for the good of an Indian community but not for research purposes. If you choose to work for the good of an Indian community, you just file and forget your manuscripts. That's a real issue, and I'd like for you to consider that and discuss it together at a future time.

With regard to Dr. Walter Hillabrant's paper, *Research in Indian Country: Challenges and Changes*, I agree that the stakeholder often is the federal government. Funding for Native American research projects usually comes from the federal government, or less often, a Robert Wood Johnson foundation fellowship or someone else who's interested in providing funding. Most of the research, as you know, is budget driven, and if you don't meet the federal funding criteria you're not going to get funded to do that research project. Research is not often a priority for tribes. It's not a funding priority. So when they go to the federal government or when they go to the Hill asking for funding, you can bet it's not going to be for research, except to the extent that it meets their needs assessment value.

We all know that Indians often fail to submit compelling proposals in their applications for competitive funding. I know this to be so particularly in prevention, because we get calls from tribes that haven't qualified for a grant and are often disappointed with rejection letters from funding agencies. They express needing assistance with needs assessment or to obtain results and findings of research based on Indian population samples. I also think that the kinds of research designs submitted by most of the competitive applicants are not generated by tribes. I suspect that most of the research design is really done at the university level and then presented to the tribes for their reactions, so there's not a proactive involvement.

Dr. Hillabrant, you talked about the sampling problem and I, like Dr. Spero Manson, agree that it is definitely a problem. It is one of the reasons we cannot get valid and reliable data. Let me given you an example. Two years ago, at the Department of the Interior, we tried to collect child abuse and child neglect alcohol-related data. We had data from 1992 to 1996, analyzed it, and reported summaries to tribes. In some cases, we were able to compare tribal data with regional data and national data. But the tribes quit collecting data after 1996 because of the Indian Self-Determination Act. When that law was passed the tribes were no longer required to collect data, and that has left us with a serious sampling problem, since only a few tribes report data to us.

The Substance Abuse and Mental Health Services Administration conducts a national Household Survey (HHS/SAMHSA Household Survey) in which they have to oversample in order to determine a profile for the Native

American populations. I agree with Dr. Hillabrant that if research is going to include Native American samples, then the design has to include some additional costs or the costs have to be built into the design.

I think what is also missing is some attention to the fact that tribes need to be involved in data interpretation. I didn't see that in any of your papers. That's so very critical, because researchers are now looking at a lot of cultural variables. And if you're going to look at culture, you need to make sure that it is interpreted with some cultural validity. I would caution non-Indian researchers to really be careful in how they interpret the culture data. Sometimes it is not so obvious and not what it appears to be. Sometimes the population being studied will show you something just to please you. So you have to be very careful.

Dr. Hillabrant, in your paper, I felt that you did not sufficiently differentiate research and evaluation. We certainly want tribes to apply the knowledge gained from research. And most of us believe that tribes should have an evaluation and research agenda. There's a need to collect evaluation data, and I think many tribes would rather collect and do evaluation than focus on research or spend money on research. It seems to me that when tribes have a choice, they will look at evaluation. For the federal government, evaluation is probably very critical. Then I think you need to look at some of the variables that Native Americans pay attention to in program evaluation. The federal government pays attention to accountability, and that's where Indians tend to fall behind within their program evaluation. Indians have not been taught some simple ways to conduct evaluation. Basically, program evaluation in Indian communities is critical and it needs to be done from an Indian perspective.

As I said, tribes can probably relate more to evaluation than to research because they see a benefit from receiving it. I think most tribes look at evaluation as a tool to determine if their services delivery activities are, in fact, effective. I think they are now at the point where they are willing to look at that objectively. Sometimes they do rely on their research consultants who come in from outside the reservation and conduct program evaluations. What I would like to see you explore is how to help tribes develop that kind of capability. Research and evaluation can go hand in hand, but you need to make sure that the tribes see that distinction and that relationship. There is a lot of research needed in order to collect baseline data. Baseline data is often not there, and most programs cannot do effective evaluation because they do not have any data to compare their program results to. I would like to conclude with a statement that you made, Dr. Hillabrant, that tribes need to get behind the research field. I think that's where it's at.

Dr. Paulette Running Wolf's paper, *Cultural Competence Approaches to Evaluation in Tribal Communities*—I agree with your very first statement, Paulette, when you said our discussion here should not be limited to disability research and evaluation. The designs, procedures, and reports of this research have often been implemented without regard to the cultural systems or the cultural competence of the subjects. I think the monograph you are preparing through this symposium will have some valuable implications for policy at both the tribal and the federal government levels as well as the program level. I think the Department of the Interior will be able to use some of your findings and some of your research, for example, to develop stronger policies for alcohol and substance prevention and violence prevention.

You raised the point that much of the current research is based on western psychological theory that is contrary to the values, structures, and worldviews of tribes. I agree with you. The evaluation methodology that you discuss in your paper demonstrates what Indian researchers can do creatively. I wouldn't say that non-Indian researchers cannot do this kind of creative work, but I think it's easier for

Native Americans to do it because they have the cultural experience.

A particular strength in your paper is your reference to the development of culturally appropriate assessment instruments. I like that, and I'd like to see more of it. We at the OASAP [Office of Alcohol and Substance Abuse Prevention] can put that information on our technical assistance web site and make it available to Indian tribes.

You point out the importance of identifying methods that would enhance the cultural relevance of research in tribal communities. You also raise the issue of what is means to be healthy. I see that as a challenge, and I'd like to see further development of that discussion.

Basically, I didn't see anything in your paper that I thought could be interpreted as negative. I believe the paper shows some far-reaching implications for policy. There is one caution that I noted—perhaps more of a suggestion. I would like to have some consideration or rethinking in relation to the concept of "cultural competence," to consider looking at it from a bicultural perspective, because I think biculturalism is the reality of most of the tribes. We don't live in a "traditional cultural world" any more. I think that when we talk about our cultures, most Indians talk as if there's one cultural context. So we talk about something that's abstractly Native American when, in fact, we don't really operate that way because we don't have autonomy. We are part of another system. We can't flourish and survive unless we work with the American culture. So American culture is, in fact, part of Indian culture. It's part of us. Indian people sometimes forget this. Researchers try to make rigid categories and forget this reality. There's also another dimension, and that is there are so many intermarriages that realistically you can't really talk about only one cultural context anymore. If you're a Navajo married to a Pueblo or a Sioux, you try to integrate those lifestyles in addition to American culture. So I would like to see some consideration of a bicultural framework for bicultural competence.

Dr. Catherine Marshall, I don't know enough about disability research to feel confident critiquing the paper, *Community-Based Research and American Indians with Disabilities: Learning Together Methods that Work*, but to the extent that it deals with Native American research I have some comments on it. You stated that we must begin to function with research design that's actually based on culture; coming from a cultural orientation myself, I felt that was a very strong statement. You talk about key collaborators, and I agree that you definitely need that. However, I also would throw in a caution about key collaboration. A Native American might interpret that as almost patronizing. It might look to some Native Americans as if you're using Native Americans for a gain, a research gain. Now, I'm saying this because as a researcher, I think you need to be aware of it. I am not saying that all Native Americans will look at it that way, but I would recommend that you maybe rethink that. I do want to say that in terms of disabilities research, I don't think there are enough Native Americans out there with that expertise, so you probably will not find many Native Americans to collaborate with at the professional level on that research topic.

You talk about culturally sensitive methods such as listening. I agree with you. I think that we all need to do a little bit more listening.

I like the statement you made about cultural disability among the Australian Aborigines. I think that can be extended to the Indian populations as well, and can cause social disadvantage. I like the strong statement that you made about equal partnerships. That is what will make Native American people encouraged, agree, and respond.

With Jennifer's paper, *Learning from and Working with Yup'ik Professionals*, I got really excited about the collaborative research on the project. I've always seen the Yup'ik tribe as exemplary. When I worked for the U.S. Department of Education, the Office of Indian Education Programs sought out exemplary

programs and Yup'ik was one of their outstanding education programs. When I read your paper, I had a great sense of appreciation and some background on your subject. Your paper was very smooth. The methodology was detailed. A strong partnership with Yup'ik certainly stands out. I think the analysis that was done of the Yup'ik culture is also presented with a lot of respect, and I gained further respect for the Yup'ik culture as I read the paper. I just had two or three questions. I didn't know how much you involved the Yup'ik people in terms of goal setting. And I didn't see information on how you plan to involve the Yup'ik in interpretation of the findings.

Basically, the Yup'ik study has far-reaching implications for policies at the school level and the level of early Head Start programs. We need to have the Alaska Native populations work more closely with the state. They're having so many problems and I feel that's where we can try to help at the policy level. I also think some of the foundation you have laid for the research will certainly provide much guidance to the federal government.

I do have one more concern: I would have liked to have seen your research team include some kind of component that would help develop some internal capability within the Yup'ik on doing research and evaluation. I think that's very critical because it's still a very viable culture and a very active linguistic culture. They cannot continue relying on out-of-state researchers. At some point we would like to see them prepared with some research skills, as well.

In conclusion, I don't know if I did justice to the papers. I felt you all did such a wonderful job. As I think of the value and the energy that you put into your papers, I ask: What can we do with this work and its implications? I would like to see a second symposium, and I'm committed to talking to the Assistant Secretary of Indian Affairs, who has a major trust responsibility with the American Indians, to see if he would be interested in initiating an interagency effort to see that this gets done.

I think we need to keep this momentum of intense discussions on Indian research issues alive. We need to bring other federal agencies such as SAMHSA [Substance Abuse and Mental Health Services Administration], OSERS [Office of Special Education and Rehabilitative Services] and DOJ [Department of Justice] to the table. The DOJ, for example, has an interest in Indian research and its application to the tribal and federal levels. We have already had one meeting on this topic. We also need to involve the National Science Foundation. I understand they are bringing Indian educators together to talk about Indian research in May. So there are a lot of people interested, and there are a lot of programs looking for answers on issues brought forth in your papers and discussions at this forum.

What can I do from my position? I think we can probably start identifying our other federal partners to see if there might be an interest to bring these issues to their agenda. I am, for example, interested in examining some of the funding criteria for research funded by the federal government. I think even the Office of National Drug Control Policy at the White House would be interested to come to the table as well.

I think the work that you're started has some major implications. It has the potential to go beyond what has been done before. Nobody has really come to the table and started ironing out some of the pros and cons of Indian research with people who have disabilities. So I see this as a very positive step in the right direction. I would like to offer to help be part of the process to move this effort beyond today's session.

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Dr. Catherine Marshall: One thing—Holly helped me with this—when we were talking about how to prepare to come here she said, "Take it back to your purpose. Take it back to your proposal." And so one thing I'd like to take it back to, and maybe Howard has a comment, is this: I think it is really important for us to keep in mind that AIRPEM came out of disability, including behavioral health issues.

Ms. Priscilla Sanderson: Yes. And we want to do capacity building in Indian communities to bring more disabled researchers on board. I think there needs to be a process of mentorship and some sort of standards to help us out.

Dr. Velma Mason: When I said I would like to put an agenda together that would look at some of these research needs with other agencies, that's kind of what I had in mind. This is not to offend any of you researchers who are successful applicants, but I do know that Native Americans do complain about the monopoly on research grants by non-Indian researchers who are not very ethical about sharing funds and so forth. So when I say the criteria, I'm looking at maybe bringing other federal funders and agencies together, and start talking about some of those issues.

Dr. Paulette Running Wolf: What we're talking about is the fact that we don't have enough Indians doing research in Indian country. How do you get there? How do you get there as an Indian person? So that's a separate issue but I agree we need to have that mentorship process. A lot of junior researchers really are looking for mentors and there are people who really want to partner up with Native American researchers. And I think that's a major role. Earlier I talked about cultural oppression. I still am subject to a lot of oppression, racial oppression. . . . People don't talk about it. People try to hide it under the table but it's still there. It's still there. And some researchers won't talk to you unless you're a bona fide senior researcher, you know. I was lucky enough to go to school at Western where Joe Trimble was and then he had me go to school where Teresa LaFromboise was. So I had that mentorship process. And Art McDonald was my APA mentor. So, you know, I think that process of reaching back and helping each other needs to be there, and that is broadly across all fields.

Ms. Jill Shepard Erickson: The new administration is coming in with a very strong message for an evidence base for everything that we do. Fortunately, with our grant program, we have very strong tribal participants who are pulling the cultural and spiritual piece into the system of care for children with special needs. We know in so many different realms how important the cultural piece is, the intergenerational trauma. And in the four years that I've been at SAMHSA, where we're serving the whole country and all of the cultures, we get some backlash in our office for serving disproportionately the tribal population because, you know, we're less than 1% of the nation. Our office has been involved with the Surgeon General's report on disparities in mental health, the basic four cultural and racial and ethnic groups. I'm not a researcher, I'm a social worker, and it was the first time I'd really been aware of the "gold standard of research," which the ethnically specific research centers are never going to meet with our [relatively small] numbers. It's impossible. I think that's a challenge. It's a desperate need that we have in the field of research to make a case for the concept of the intergenerational trauma and how that impacts the history and how we can build on it. There's a renaissance happening in Indian country today. I was thinking about my mother's people, after four generations to go back to the ceremonies . . . The communities have been doing the healing work in different

forms in different tribal communities in the past five to ten years. I just hope that we can preserve that and continue to support the work. As a federal agency we have money to give away to tribes to do things if they can find grant writers who meet the standards. We tend to see the same tribes getting the grants, but at least if they're making points that other tribes can take advantage of, that's to the good. I guess that's something that I would like to see come out of this work that we're doing, and also, if we're going to look to another symposium I'd really like to include The Association of Tribal Colleges. Because I think that's where we should be looking for mentorship—also to build the capacity of the tribal colleges.

Final Discussion and Summary Comments

Holly Echo-Hawk, M.S., Facilitator

Ms. Holly Echo-Hawk: You said in your information packet that the goal of AIRPEM is to explore, share, and document American Indian cultural considerations regarding best practices in research and program evaluation. You went on to say that AIRPEM understands four things. First, AIRPEM understands the importance of tribal consultation when proposing research. Second, AIRPEM understands the importance of research that benefits American Indian communities. Third, AIRPEM understands that cultural factors affect the research process. And fourth, AIRPEM understands that the diversity of tribes should be considered.

So, out of that foundation of AIRPEM and AIRPEM's statement of understanding, you decided to solicit writings to be compiled in a monograph. And you have listed seven groups as your target audience for the monograph: researchers, evaluators, health and human service professionals, private practitioners, national tribal advocacy organizations like NCAI [National Congress of American Indians] and NIHB [National Indian Health Board], etc., federal agencies that you either partner with now or want to expand partnership with, and the last one, which Velma spoke to, is policy makers.

Given your goal, AIRPEM's goal, your stated understandings, the monograph concept, and whom you want to target, and based on the discussion that happened yesterday and today, I started creating a list of standards for the monograph, a framework for the monograph.

1. First, you want to make sure that the monograph obviously reflects an American Indian and Alaska Native voice and perspective throughout.

2. It also seems that you want to make sure that the [presented papers] have American Indian or Alaska Native authorship or co-authorship. This is part of "walk the talk."

3. Third—which we didn't really talk about but which I wanted to raise at least for discussion—it seems you want to make sure that you have American Indian or Alaska Native publications to back up your work—not *only* Native documentation, but you at least want to have a balance of non-Indian and Indian perspectives in terms of research and program evaluation. We know that there are many publications authored by Native Americans or Alaska Natives.

4. An additional standard for discussion is the postcolonial stress participatory action research framework.

5. To look at the strengths and protective factors, instead of using exclusively a deficit model, which has been the trend in the past—to balance that or exchange that for an emphasis on strengths and protective factors, instead of researching strengths as an afterthought.

6. Next is locally meaningful constructs. I think Paulette was speaking to this in her examples in her [paper]—making it meaningful to the local perspective.

7. The commitment to acknowledging tribal and linguistic diversity, which Velma spoke to this afternoon.

8. And a mechanism for change—that was a theme in the discussion and Spero spoke about it yesterday. I know that you don't want this monograph to be something that just sits on a shelf. You want it to be done in such a fashion that it really is a mechanism for change.

9. And don't patronize. Everyone will say, "I would never patronize." Well, what I'm saying is, double-check the language in your [papers],

because in my experience, especially from academic perspectives and scientific approaches, there's a tendency in just the language of your training that makes a lot of sense to fellow scientists but from a tribal perspective it really does come off as patronizing, even when it's not intended. So I suggest that you double-check the language in your [papers]. Or better yet—if you have not already done so—have the tribal people you're speaking of in your [paper] review it *with the freedom to be critical.* A lot of people will review it and then give it back and say, "Oh, it was fine." Well, it really isn't fine. They really need some permission to be critical and frank in their review—to say that the language may be too sophisticated, too scientific, too exclusive. A lot of times people will pass it off to local folks to review, and either they don't have the time or they don't feel they really have the permission to be frank, and they give it back and say, "Well, it's okay." And then the researcher takes it and runs with it and says, "Well, I had it reviewed and it's all okay." So I'm just reminding you all, from my experience, to double-check your language, because it can come off as patronizing.

Ms. Priscilla Sanderson: Yes. I think just giving them a paper and saying, "Read it" is not enough. I think actually sitting down with them and giving it paragraph-by-paragraph and then doing a discussion would be more helpful.

Dr. Jamie Davis: Velma, earlier you asked, "To what extent is true collaboration possible?" Given the tension between science and advocacy, perhaps I am still an optimist—and I hope always will remain an optimist—but again I think this really speaks to the issue of true collaboration. It's not, "Here, read this paper. Here's the research design." It speaks to what Spero was saying. It's a lengthier process—it takes "sitting down." And, you know, what we or other researchers do by doing that is that we mentor people. I don't think that only a Native person can mentor me. One of my best mentors was non-Indian. She was of another tribe, the Jewish tribe. Really, it's about sitting down and taking that time, and not seeing it so much as research but as a process.

Dr. Paulette Running Wolf: Maybe we should be asking for direct, honest feedback from even more than one voice, too; that would speak to Joe's comment about factions of the communities.

Dr. Robert Schacht: What we do in the community-based needs assessment research is have a community meeting to present the results of a study, so we can get community feedback.

Ms. Holly Echo-Hawk: Even in community meetings, which I think are fabulous, in my experience a lot of times tribal communities go to community meetings sort of like entertainment, so it doesn't always work as well as we would like it to.

So, those are some ideas for standards, based on all the discussion and the critiques from the three reviewers. Is there any disagreement with any of these? Are there additions?

Dr. Velma Mason: Cultural diversity. Do you have cultural diversity or just tribal diversity?

Dr. Paulette Running Wolf: You know, Holly, as we've gone through this process, we're really starting to generate a list of recommendations for conducting culturally appropriate research in Indian communities.

Dr. Catherine Marshall: Some of what we're talking about here is actually in a paper by Justin D. McDonald, *A Model for Conducting Research with American Indian Participants*—a wonderful document. If we can get permission to reprint it as an appendix, that would be a very good thing. So we're adding to the wheel that has already been created...

Ms. Priscilla Sanderson: I think I may just be a little bit more sensitive because I come from a reservation where a majority of the policy makers speak Navajo. I think if you give a report to a tribal council member and ask them to read it, I don't think they'll read it. I think you have to have a translator to talk with them

in Navajo about some of the significant findings and how the research process occurred, the methodology, and so forth. So I really think that my early comment about just reading paragraph-by-paragraph relates to translation.

Dr. Lee Parks: I think that argues for different formats.

Dr. Howard Busby: How about sign language, also?

Dr. Robert Schacht: Spero referred to the efforts of the '60s and the '80s, and I'm wondering if there are comparable things from those efforts to encapsulate in some way, and honor and acknowledge.

Dr. Paulette Running Wolf: For sure the Barrow study should be incorporated, all of the Barrow studies. There was a whole series of articles that Joe [Trimble] and Teresa [LaFromboise] and Carolyn [Attneave] wrote; folks reacted to that study.

Ms. Beatriz Mitchell: I used to be a special assistant in OSERS [Office of Special Education and Rehabilitative Services]. I'm looking at the policy perspective. As a policy maker, who do we want to read the monograph? What does the monograph need to say to a policy maker regarding our wishes, our hopes? What do we want the policy makers to do with this monograph? What is our intent?

Ms. Holly Echo-Hawk: If you're sending your monograph to policy makers, one of the approaches that I've seen is to have a separate policy brief. Sometimes it will give suggested language on how to tweak things; frequently a policy changes just by adding a few words. And you may want to pull together a conference call with your policy folks after this symposium, just so they can brainstorm on how to most effectively reach the policy makers.

Dr. Velma Mason: I still think it's important to list as a standard the involvement of tribal folks in data interpretation.

Dr. Paulette Running Wolf: Design. Research design and interpretation.

Ms. Holly Echo-Hawk: Why don't we say "design to interpretation"?

Dr. Jamie Davis: It actually probably begins before design.

Ms. Holly Echo-Hawk: We'll put predesign.

Dr. Catherine Marshall: Planning.

Ms. Holly Echo-Hawk: Predesign all the way through interpretation.

Dr. Robert Schacht: Definition of a problem.

Ms. Holly Echo-Hawk: Definition of a problem or definition of wellness?

Dr. Paulette Running Wolf: Bob mentioned something that I think should be included: an acknowledgement of the tension around doing research.

Ms. Holly Echo-Hawk: There's a premise that we talked about in this whole symposium: "First do no harm"—and that underlines everything that we've all talked about from day one.

Dr. Jennifer Olson: If I could just add, "and do good to everyone." There's this other half to "do no harm"; there's also a purpose. Do good, no matter to whom. Because sometimes we don't know where the ripples will be, which river our stream will end up in.

Ms. Holly Echo-Hawk: There are three things that kind of fell out of the standards but need to be recaptured. One is that somebody said that the monograph needs to reflect a problem-solving approach to the tensions, that all of those tensions—a pretty significant list—are a whole category that you want to give some more thought to. The same thing with the science-versus-advocacy issue. That is one of the tensions. Spero spoke to that very clearly; his question, I think, was "Do we as researchers have the skills to do this? There may be a moral urging to do this, but is the skill set there to do this?" And then the third one is capacity building.

Dr. Walter Hillabrant: I can't resist one thing

because it's so fundamental to my perception of reality; I want to go back. The idea of "first do no harm" is ridiculous. You can never do anything that doesn't have costs as well as rewards. Take inoculations. If you give 50,000 inoculations, which is the right thing to do, you know in public health that one of those kids is going to die. You can't pick anything that doesn't have rewards and costs associated with it. I don't mind if we say "first do no harm" as long as we acknowledge with a footnote that it's not really true. You're deluding yourself if you think what you're going to do is purely good.

Ms. Sharon Johnson: I think there's a difference, though, between doing harm out of cynicism and callousness and doing harm out of innocence in an attempt to do good.

Dr. Walter Hillabrant: Yes and no. The road to hell is paved with good intentions, and those people whose kids die from inoculation are never going to care that you were doing it to do good—and if you don't admit that you're going to be incurring those costs you're deceiving yourself.

Ms. Deeda Williams-Joseph: How about "first do no intentional harm"? I mean, that's what you're saying.

Dr. Walter Hillabrant: No, it's not. My real underlying point is that you intended. When you do those inoculations you can blindly say, "My intention is to promote public health," but if you don't accept the fact that you are causing the death of 1 out of 20,000 kids, you're deluding yourself.

Dr. Howard Busby: I think you're looking now at a medical perspective, a medical model, while here, we're speaking of a humanistic model. I see those as actually two very different things. I believe you can have good intentions and still harm, but from a medical perspective you save as much as you can at all costs. Whereas here, from a human perspective, we need to make sure that everything we do does not result in harm.

Dr. Catherine Marshall: Let me side with Dr. Hillabrant on this one just because I feel that—to quote Barbara Kingsolver—"Everything you know to be good is wrong some place else." Absolutely by definition. Everything you know to be right is wrong some place else. And so from the cross-cultural and cultural-context perspective of research with Indian people with disabilities, I do believe from the outset that, in fact, anything we believe is good is, in fact, wrong and bad somewhere else, and you can't get out of that trap. You can only hope to be forgiven and excused.

Dr. Jamie Davis: I would like to say that everything we do has impact and so I certainly agree with that. We're not to judge what's right or wrong about that impact, necessarily, but I think the premise, the intent behind the statement, is what is important. Not the theoretical implications. And that's why it's a statement in psychotherapy. You're right, we're all right, we're not going to solve it now, but I really think the intent behind it is what is incredibly powerful and important.

Dr. Velma Mason: Holly, I think there's another point that Jill made that got left out: the Native American populations evidence-based programs; that's program evaluation. As a standard, maybe researchers should be able to commit to assisting tribes in developing that kind of capacity.

Ms. Holly Echo-Hawk: Velma is saying that Jill brought up the evidence-based requirement and urgency from outside sources, particularly federal, as another category that needs to be not forgotten. Many people's response to that has been that the definition of "evidence-based" evaluation needs to be broader. Generally, then, the whole category of evidence-based requirements and how to address that.

Dr. Jamie Davis: The way I understand how the evidence-based evaluation works is that tribal programs are required to show some evidence at the end of their project, and most tribal programs aren't able to do that because they don't have the research and evaluation

expertise that you all have. Maybe this is something that you can help tribes develop capacity for.

Ms. Holly Echo-Hawk: And what I'm hearing is that evidence-based [evaluation] is an issue that this group needs to think about.

Dr. Paulette Running Wolf: I appreciate Jill bringing that point up, but I think it's more than an issue—that it is a challenge, to identify other methods of supporting culturally relevant treatment methods. There are other methods of demonstration of success, of efficacy. There are other ways to do that, and they may not be purely quantitative. It may be a qualitative collection of case studies; it could be a combination of things.

Dr. Elizabeth Kendall: We went through that in Australia. We had the evidence-based standards of quantitative randomized controlled trials before you could get funding—and part of this group's responsibility is to challenge that. That's what happened in Australia. And now funding is linked to *qualitative* research, instead. So I think that whole process can change.

Ms. Holly Echo-Hawk: One of the resources that a follow-up group may want to look at is the standards-based work from Australia and New Zealand—some of the finest work in the world, I think, in terms of developing standards from a policy perspective.

Dr. Catherine Marshall: Regarding research and evaluation and intervention of any kind, I think the best example in our papers was from Paulette's paper, where one group said, "Let's take the information from research and use our informed consents to hand that over to clinical intervention." That's always a tremendous issue, and that's the first time I've ever seen a clear example of where that has been done.

Dr. Jamie Davis: There is also a model with marriage and family therapy; if you've got a couple coming in and the husband is beating his wife and you're passive, you're in trouble.

Ms. Holly Echo-Hawk: In the category of next steps that I was hearing discussed, there will be another symposium of sorts to pull together and link with other resources, other federal groups. And then there is the dissemination of the monograph, which has become more powerful and more important, in a sense, just over the past couple of days.

Dr. Catherine Marshall: This symposium is a group of the people who could come today, a group of *some* of the authors. There's a bigger AIRPEM group as well.

Dr. Jamie Davis: As a next step it seems to me it's for the AIRPEM membership to decide how often we'd want to communicate or meet, if we want to do something somewhat regularly.

Dr. Catherine Marshall: But one thing I want to say is that we're not a membership organization. There are no AIRPEM members. We are folks who have come together. It's been word-of-mouth—who do you know who might be interested. It's your responsibility—if you want people involved, you call them up. Nobody is in charge here. We are a leaderless group.

Ms. Holly Echo-Hawk: This is a little different kind of organization because there's nobody responsible. Really, there's no membership. It's people who do research and program evaluation with Indian people who have disabilities. So I'd hate to see us get people who are philosophical or whatever, because we're kind of grunt work people, you know. It's a support group, really.

So, let me go over some closing thoughts.

1. "Authentic partnership in research." The historical transition that's happened, from the research perspective, has been the movement from the old school, original approach of "doing for" or "doing harm"—let's start with that: "Doing harm" is the original. "Doing for" was the next transition. We're talking in terms of decades here. Then we moved to "do with," but it was somewhat as an afterthought—"do with" in a token way, not authentically. And

now here we are in 2002 with a whole new ball game: tribal leadership, tribal sophistication, tribal power.

2. I like to always remember how privileged we are either to be American Indian or Alaska Native or to be so privileged as to be invited into those communities as researchers and to be accepted. That's the other message I want to give, about remembering how privileged we are.

3. And then the third thing is that part of what the research field needs to do—and you all are certainly making this happen—is to help research move from being a cause of trauma to being a source of healing.

4. The other challenge that you all have is to link with all of these other entities that have been discussed without losing your focus on disability issues.

5. Along with that, you want to grow this critical mass that Spero talked about, that was lacking before—but you want to pick your battles. You want to pick your linkages, whom you're linking with, carefully and strategically. Because the challenge is, you don't want to disengage. Remember Spero talking about why things failed before? This is an old conversation that has been going on for decades. He was saying he thought it was in part because the critical mass wasn't there, and that's what's needed to keep the momentum going. So it's important to grow the critical mass. That's what you're doing through the monograph, but you also have to pick whom you're linking with strategically, because it can become very overwhelming very quickly.

6. The last thing: I thought it was very profound that Walter said with great passion—as a matter of fact, he looked down and didn't look up when he said this—that researchers need to be brave, they need to be strong, and they need to be smart. And I would add: they need to be strategic.

Part IV
About the Contributors to the Monograph

About the Authors

Howard R. Busby, Ph.D. (Mississippi Choctaw-Eastern Cherokee)

Howard Busby is of Choctaw descent (Mississippi Band). He has spent his entire professional life working with Deaf and hard of hearing individuals in a broad spectrum of capabilities. He has held the following positions: teacher (all grade levels), coach (football, basketball and wrestling), counselor, rehabilitation services coordinator, teacher educator, counselor educator, director, dean, and vice-president of a university. Howard has a bachelor's degree in education from Southern Illinois University, a master's in special education administration from California State University-Northridge, a master's in counseling from the University of Kansas, and a doctorate in counseling and educational psychology from the University of Arizona. He currently serves on the boards of the Maryland State Rehabilitation Council, The Client Assistance Project at NAU (where is also housed the AIRRTC), and the Intertribal Deaf Council. He currently holds the position of professor in the Department of Counseling at Gallaudet University.

Jamie D. Davis, Ph.D. (Muscogee Creek-Caddo)

Jamie D. Davis, a Muscogee Creek-Caddo from Oklahoma, began her career with Indian Health Service (IHS), an agency of the Department of Health and Human Services, as an IHS scholarship recipient, in 1993. In 2000 she accepted the position at IHS headquarters as Principal Psychology Consultant for Behavioral Health, a division of the Office of Clinical and Preventive Services, where she is working with other behavioral health staff to establish mental health initiatives for American Indians and Alaska Natives.

Jamie is actively involved in two Department of Health and Human Secretariat Services disaster initiatives, is a member of the Center for Disease Control's Coordination Team for the *Guide to Community Preventive Services*, and serves as Consulting Editor of the American Psychological Association's journal *Professional Psychology: Research and Practice*. She served as the IHS key staff member for President Bush's New Freedom Initiative, worked on the Surgeon General's Work Group on Mental Retardation and Secretary Thompson's Prevention Initiative, and served as a peer reviewer for the Surgeon General's Reports on *Youth Violence and Mental Health: Culture, Race, and Ethnicity*. Jamie collaborates with a number of federal and non-federal agencies and organizations, including the Substance Abuse and Mental Health Services Administration, the American Psychological Association, the National Indian Child Welfare Association, and other organizations whose vision is to strengthen American Indian and Alaska Native communities. A considerable portion of her work focuses efforts toward children's mental health initiatives.

Jamie's previous position was as the Clinical Psychology Associate for the Pascua Yaqui Tribe of Arizona. She provided direct clinical services to and developed prevention programs for elders, children, adolescents, families, and adults. She served on the diabetes multidisciplinary team as well as the treatment multidisciplinary review team. Jamie also worked as a crisis counselor during the aftermath of the bombing of the Alfred P. Murrah building in Oklahoma City and completed an externship with the IHS Pawnee Service Unit while working on her doctorate.

Jamie earned her bachelor of arts degree in psychology from the University of Nebraska at Omaha. She received her Ph.D. in clinical psychology, with a specialization in child clinical psychology, from Oklahoma State University in 1997. Her dissertation research

considered the influence of culture and development on sexual risk-taking decisions of Native American adolescents. Jamie completed her clinical internship at Dartmouth-Hitchcock Medical Center (DHMC) in Lebanon, New Hampshire. She remained at Dartmouth College (DC) as a postdoctoral fellow for an additional two years. During her tenure at DHMC/DC, Jamie engaged in extensive outreach to the Native American community, provided direct clinical services to all students, and earned the title of Director of Research for the Counseling and Human Development department.

Jill Shepard Erickson, M.S.W., A.C.S.W. (Athabaskan-Dakota)

Jill Erickson is enrolled as Alaska Native and Santee Dakota. She is the Program Director for the Circles of Care grant program for American Indian and Alaska Native tribal and urban Indian programs through the Substance Abuse and Mental Health Services Administration (SAMHSA). The purpose of the Circles of Care grant program is to plan and evaluate the feasibility of culturally specific systems of care for children with serious emotional problems. She also serves as project officer for tribal grantees in the Child Mental Health Initiative. Previous experience includes working as a social worker for the Indian Health Service (IHS) in direct services at Rosebud, South Dakota, Pendleton, Oregon, Phoenix, Arizona, and at the Headquarters West Mental Health Program Office in Albuquerque, New Mexico. She received both a bachelor of science and a master's in social work from Portland State University, Oregon, majoring in planning, community organization, and management.

Calvin Hill, B.S. (Eastern Band of Cherokee)

Calvin Hill is the Supplemental Health Insurance Program Manager for the Eastern Band of Cherokee Indians in Cherokee, North Carolina. His responsibilities include everything from disability claims to resource development. A member of the Eastern Band of Cherokee Indians and a former on-site research coordinator for one of the American Indian Rehabilitation Research and Training Center research projects, Calvin has continued his work with members of the Cherokee community who have disabilities by assisting them with alternative fiscal resources. His involvement with research and coordination is evident in his role of developing new/alternative programs and planning/consultation related to Medicare, Medicaid, Indian Health Services, and "interpreting large systems programming" to the Indian population—bridging the gap between the old and the new, traditional versus modern.

Walter Hillabrant, Ph.D. (Citizen Potawatomi)

Walter Hillabrant has over 30 years' experience working on behavioral health research, clinical psychology, program evaluation, and policy analysis. He serves as the Technical Director for the Committee on Benefits of the National Council on Alcoholism and Drug Dependence (NCADD). He is a clinical psychologist, licensed in the District of Columbia where he maintains a small private practice.

Since 1980, Walter has worked at Support Services International (SSI), a consulting firm specializing in research and training in the areas of health, education, welfare, and economic development. From 1970 to 1980, he was a professor in the psychology department at Howard University. He earned a doctorate in psychology from the University of California at Riverside in 1972. Walter is enrolled in the Citizen Potawatomi tribe.

Walter is currently working on the national Wefare-to-Work evaluation and is directing a small business innovative research project funded by DHHS/ACF to develop decision support materials to help tribes decide whether or not to take over the TANF program. He directed a recently completed multiyear prospective assessment of the addiction treatment outcomes of Native American women for the Indian Health Service (IHS).

Walter has also directed studies of residential addiction treatment programs for Indian adolescents, family violence in Indian country, the quality of life of Native American youth, and vocational rehabilitation programs. Walter has been an expert witness (evaluation and statistics) in federal court for the Justice and the Health and Human Services Departments on five cases involving services to the handicapped (*Pace v. Hannon*), special education (*Larry P. v. Riles*), and civil rights.

Sharon R. Johnson, B.A., CRC (Minnesota Chippewa Tribe, Fond du Lac Band)

Sharon Johnson has been a rehabilitation counselor for the State of Minnesota, Division of Rehabilitation Services, since 1976. During that time she has provided vocational rehabilitation services to American Indians living on reservations in Northern Minnesota. Herself an enrolled member of the Minnesota Chippewa Tribe, Fond du Lac Band, she has worked to develop a service delivery model that involves a counselor and a case aide working as a team to provide culturally appropriate service to American Indians with disabilities through the public vocational rehabilitation program. A Certified Rehabilitation Counselor since 1992, Sharon graduated from the University of Nebraska at Omaha (1969) and is currently a master's degree candidate at Minnesota State University-Mankato. She has co-authored three articles, and a final research report entitled *An Evaluation of the "Counselor plus Case Aide Model" in Serving American Indians with Disabilities Through the Public Vocational Rehabilitation Program.* Most recently, she co-authored a chapter entitled "Best Practices for Serving American Indians in Vocational Rehabilitation: A Clinician's Perspective," published in *Rehabilitation and American Indians with Disabilities: A Handbook for Administrators, Practitioners, and Researchers.*

Kelly Keemer (Seneca)

Kelly Keemer, a Seneca from Rochester, New York, is currently a student intern at Indian Health Service (IHS), an agency of the Department of Health and Human Services. At IHS she works under the supervision of Jamie D. Davis, Ph.D., in the Office of Behavioral Health. Kelly is a junior at Ithaca College and plans to graduate May 2003 with a bachelor of science degree in community health education.

Elizabeth Kendall, Ph.D.

Elizabeth Kendall has a B.A. in psychology and special education and post-graduate qualifications in psychology. She has been researching in the area of traumatic injury and disability for over 15 years. Elizabeth completed her Ph.D. in 1997 on adjustment following traumatic brain injury and received the Dean's Commendation for Outstanding Ph.D. Thesis (University of Queensland). She is the foundation Research Director of the Centre for Human Services (Rehabilitation), where she manages and supervises the development of an international research agenda in the rehabilitation of injured individuals. In 2001, Elizabeth was appointed as Associate Professor of Social and Behavioural Sciences at the Centre for Human Services and is an Associate Director of the Disability, Injury Management and Rehabilitation program at the Centre for National Research on Disability and Rehabilitation. She has maintained a personal research agenda in the issues faced by indigenous and rural people with acquired disabilities or chronic conditions. In addition to her research career, Elizabeth volunteers at many worthwhile disability and community services, including horse-riding for people with disabilities.

Brigitte Manteuffel, Ph.D.

Brigitte Manteuffel is currently employed by the Atlanta office of ORC Macro, a private evaluation consulting firm, where she is the

principal investigator for the national evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program. This program, which provides grants to communities to establish systems of care for children with serious emotional disturbance and their families, is supported by the Center for Mental Health Services in the Substance Abuse and Mental Health Services Administration (SAMHSA). Brigitte earned her doctorate from the Institute for Liberal Arts at Emory University, where she studied psychoanalytic and anthropological theory, focusing her research on the intersection of psychological and cultural frameworks and physical health. Prior to her work at ORC Macro, Brigitte conducted HIV/AIDS prevention research with young adolescents and their mothers.

Catherine A. Marshall, Ph.D., CRC

Catherine Marshall is Director of Research and Research Professor at the American Indian Rehabilitation Research and Training Center (AIRRTC) located at Northern Arizona University in Flagstaff, Arizona, where she has been employed since 1989. Catherine has been involved in rehabilitation research for almost 20 years and has worked as either a counselor or educator in rehabilitation for almost 25 years. Prior to her work with the AIRRTC, she was the coordinator of the undergraduate rehabilitation education program at the University of Northern Colorado. In addition to investigating the rehabilitation needs of American Indians with disabilities, her research interests include the needs of persons with severe and persistent psychiatric disabilities, family and disability issues, the rehabilitation needs of indigenous people in Latin America, and women and disability. Catherine was selected for a Fulbright Scholar Research and Teaching Award (January-September 1997); the principal purpose of the Fulbright Program is to increase mutual understanding between the people of the United States and the people of other countries through educational and cultural exchanges. Through the Fulbright Scholar award, she continued her work in Oaxaca, Mexico, which was sponsored for six years by the National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitation Services, U.S. Department of Education. In 1997, Catherine was the National Council on Rehabilitation Education (NCRE) Outstanding Researcher of the Year (co-recipient with Mikel Johnson for research regarding American Indian families and chronic health/disability issues). She has published more than 20 juried articles or chapters related to rehabilitation practice, multicultural counseling, or international rehabilitation. She recently edited a book titled *Rehabilitation and American Indians with Disabilities: A Handbook for Administrators, Practitioners, and Researchers.* Catherine obtained her Ph.D. in 1985 from the University of Arizona; her doctoral dissertation was titled *Stress Reduction through Skills Training in Families of the Severely Psychiatrically Disabled: A Rehabilitation Psychology Approach.* She is also a graduate of Berry College (1972) in Rome, Georgia, and of Boston University (1977).

Jennifer J. Olson, Ph.D.

Jennifer Olson is Associate Professor of Education, University of Idaho. She teaches in the Teaching, Learning and Leadership Division for the College of Education and is the Training and Technical Assistance Coordinator for the Center on Disabilities and Human Development. She has worked as a consultant and in-service trainer with early childhood organizations for the past 15 years. Her areas of interest are family partnerships, team building, organizational change, and family literacy. She has been the director or co-director of federal projects from the U.S. Department of Education and the Idaho State Department of Education. She is currently the director of a three-year training grant from the U.S. Department of Education to provide in-service training to early childhood professionals with an emphasis on Head Start

programs. This project, Building Effective and Successful Teams (BEST), has developed and disseminated self-directed modules for Head Start personnel throughout the region, with a particular partnership with the state of Alaska. She has been a consultant to persons working with and of Native Alaskan descent for the past five years.

Philip D. Olson, Ph.D.

Philip Olson is Professor of Business, University of Idaho. He consults with Head Start programs throughout Region X. He frequently works with management/leadership teams on the topics of organizational planning, change, restructuring, expansion, quality, and team development. He has been an active researcher on the topics of organizational planning, in-service training strategies, and team development during his 30 years as an academician. His research appears in journals and he presents it at national and international conferences. He is the external evaluator for Project Northern Lights in Anchorage, Alaska.

Lenea K. M. Pierzchanowski, M.H.R.

Lenea Pierzchanowski received her master's degree in human relations from the University of Oklahoma and specializes in family and child development as well as diversity and culture. She is currently working with the BEST (Building Effective and Successful Teams) project at the University of Idaho as a training and curriculum specialist. She previously taught overseas (Japan and Italy) for the University of Maryland and Central Texas College in their early childhood education programs. She was a facilitator for the PREVENT (Personal Responsibility & Values: Education and Training) program in Naples, Italy. Other positions she held in Naples were Director of Family Childcare and Training and Curriculum Specialist for the Naval Child Development Programs.

Teresa Pingayak (Cup'ik)

Teresa Pingayak is a Head Start Regional Manager for Rural Alaska Community Action Program (RurAL CAP). She was an active partner in the participatory action research project between RurAL CAP and the University of Idaho, which included in-service education in team building and the development of a continuing home visitor's project to assist in meeting the needs of young children and their families in five Yup'ik villages and one Cup'ik village in Southwestern Alaska. Teresa is Cup'ik herself, from the village of Chevak. Only two villages of Cup'ik people remain in Alaska. They are closely associated with the Yup'ik people; Cup'ik and Yup'ik have the same meaning: "real or genuine people."

Paulette Running Wolf, Ph.D. (Blackfeet-Cree)

Paulette Running Wolf, an enrolled Blackfeet tribal member, was born and raised on the Blackfeet Reservation. She has worked exclusively with American Indian communities throughout her career in education and social services. Prior to obtaining her doctorate she worked with rural northwest and plains tribal communities in evaluation, program development, and direct services in counseling and education. Additionally, she has developed and administered several intertribal social/educational projects. Her research is focused largely on the examination of tribal-specific values and how they have continued to survive over time and with acculturation. Paulette taught for four years in the Counseling Psychology Department at Washington State University.

Paulette is currently working as a senior scientist for ORC Macro, providing site liaison services to the American Indian/Alaskan Native grant communities that are participating in the national evaluation of mental health services for children. She provides technical assistance to the tribal grantee communities in both the national evaluation protocol and their local use of national evaluation data. She also assists

with other contracts such as the creation of a national Head Start research agenda in Indian Country. Paulette has an associate of arts degree from Blackfeet Community College, a bachelor of science degree in secondary education and social sciences from the University of Great Falls, a master of education degree in school counseling from Western Washington University, and a Ph.D. in counseling psychology from the University of Wisconsin-Madison.

Rolando L. Santiago, Ph.D.

Rolando Santiago serves as Director for Evaluation and Acting Deputy Chief at the Child, Adolescent and Family Branch of the Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration (SAMHSA). He specifically oversees evaluation activities at the Child, Adolescent and Family Branch, serves as Project Officer for the national evaluation of 67 grant sites of the Comprehensive Community Mental Health Services for Children and Their Families Program, and assists with the oversight of this program that has now served over 50,000 children since it was first established in 1993. He has provided international consultation to the Panamerican Health Organization and to the country of Chile on the evaluation of mental health services. Before starting his position at CMHS in 1997, Rolando served as Research Scientist for three years at the New York State Office of Mental Health (NYSOMH) where he directed the evaluation of one of CMHS' children's grant sites located in the Mott Haven community of the South Bronx. He also helped conduct a quasi-experimental research study of intensive in-home crisis services for children and adolescents needing emergency psychiatric services. Rolando provided expertise to the NYSOMH in the areas of research, measurement, instrument development, information systems, cultural competence, and family involvement as they relate to the field of children's mental health services. He currently serves as president-elect of the Northeastern Educational Research Association. Rolando holds a Ph.D. in educational psychology and statistics from the University at Albany, State University of New York.

Robert M. Schacht, Ph.D.

Robert Schacht graduated from the University of Michigan with a doctorate in anthropology in 1973. After a number of years teaching anthropology at the university level, he was drawn to the southwest, and taught for a year at the College of Ganado on the Navajo Reservation. After a brief detour in New Mexico, where he taught in the Social Work Department at New Mexico Highlands University, in 1988 he returned to Arizona and began working for the Institute for Human Development (IHD) at Northern Arizona University. He joined the staff of the American Indian Rehabilitation Research and Training Center (AIRRTC) at IHD in 1990 as co-director of research, has served as director of research, and is currently a Research Associate. He is involved in four research projects for the AIRRTC and two additional subcontracts. His projects are concerned with specific disabilities and conditions such as alcoholism and Fetal Alcohol Syndrome, as well as labor market analyses, community-based needs assessments, and assistive technology. His research and training activities for these projects have taken him to American Indian and Alaska Native communities in Texas, Minnesota, South Dakota, Alaska, New Mexico, and California.

Robin E. Soler, Ph.D.

Robin Soler has more than 10 years' experience in research and evaluation design and data collection, management and analysis. She specializes in longitudinal and multisite intervention research and development, intervention implementation, and evaluation, with special emphasis on adolescents and their families. She has a broad range of research expertise, including both quantitative and qualitative research design, instrument

development, and data analysis. She holds a doctorate in developmental psychology. She has been involved in many large, longitudinal research projects focusing on the impact of social environment (e.g., family structure, poverty) and community-based programs (e.g., substance abuse prevention) on African American parent-child relations and adolescent development. Robin's teaching experience includes courses in race, racism, and ethnicity; thesis writing; and high school-to-college transition. Currently, Robin is a Senior Scientist and Project Manager for ORC Macro, a research consulting firm. She has been involved in the implementation of the multisite evaluation of the Center for Mental Health Services system of care program implementation for children with severe emotional and behavioral challenges. Besides contributing to the overall management and data analysis for the multi-site evaluation, Robin works closely with tribal grant communities and is examining cultural competence at many levels in the overall project.

Robin received her bachelor of science degree in psychology from Howard University and her doctorate in developmental psychology from the University of Michigan, Ann Arbor. She lives in Decatur, Georgia, with her husband and daughter.

Diane Sondheimer, M.S., M.P.H.

Diane Sondheimer is currently Acting Director, Child, Adolescent and Family Branch, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration. In this capacity, she leads a nationwide effort to build and sustain systems of care for children and adolescents with serious emotional disturbances and their families. The Child, Adolescent and Family Branch oversees the Comprehensive Community Mental Health Services for Children and their Families Program as well as Native American Circles of Care Program, the Statewide Family Network Program, and the new Partnerships for Youth Transition Program.

Prior to her 10 years at SAMHSA , Diane led the federal effort at NICHD to bring attention to the service and research needs of adolescents with or at risk of HIV/AIDS. From 1981-1988, she was on the faculty of the University of Maryland School of Medicine where she codirected a Maternal Child Health Bureau-funded Adolescent Training Grant. Diane is a pediatric and adolescent nurse practitioner with master's degrees in nursing and public health. She is currently a doctoral candidate in public administration at the American University, Washington, DC.

Katherine W. Sterling, M.A.

Katherine Sterling is a Technical Associate for the Center on Disabilities and Human Development (CDHD), University of Idaho. She worked as the University of Idaho Project Coordinator on Project Northern Lights, which brought her into a close working relationship with Yup'ik and RuRAL CAP Head Start personnel. She is presently Project Coordinator of a BIA/OIEP grant that takes three programs (Positive Behavioral Supports, Skillful Adaptive Teaching, and a course to certify paraeducators in tribal schools called "Paraeducators: LifeLines in the Classroom") into 14 tribal schools in the Northwest Region. She is acting as the Cultural Consultant for the CDHD.

About the Discussants

Spero M. Manson, Ph.D. (Pembina Chippewa)

Spero M. Manson, Ph.D. (Pembina Chippewa) is Professor and Head, Division of American Indian and Alaska Native Programs, Department of Psychiatry, at the University of Colorado Health Sciences Center. Dr. Manson directs the National Center for American Indian and Alaska Native Mental Health Research (NCAIANMHR), the oldest of the seven national programs that comprise the division. He also directs the Robert Wood Johnson Foundation's Healthy Nations Initiative, a 10-year, $15 million effort to assist 15 Indian and Native communities in their struggle to reduce the harm due to substance abuse by promoting comprehensive intervention strategies that integrate resources across formal and informal sectors of the local citizenry. Dr. Manson heads as well a $2 million grant by the Administration on Aging that established the Native Elder Health Care Resource Center (NEHCRC). The NEHCRC conducts applied research, training, technical assistance, education, and dissemination targeted to providers, planners, and administrators in tribal, urban, state, and federal aging organizations, with special emphasis on the delivery of culturally competent health care. Four other centers, each national in scope, were more recently added to the division. A Resource Center for Minority Aging Research, entitled the Native Elder Research Center (NERC), is supported by a $2.5 million, 5-year grant from the National Institute on Aging and National Institute for Nursing Research. The Circles of Care Evaluation Technical Assistance Center (CoCETAC), a 6-year, $2 million program, is part of the federal American Indian Child Mental Health Initiative coordinated through the Center for Mental Health Services within the Substance Abuse and Mental Health Services Administration. The Agency for Healthcare Research and Quality sponsors a 5-year, $4.5 million program that seeks to reduce Native elder health disparities. And, lastly, the Center for Native American TeleHealth and Tele-Education, a 5-year, multi-million dollar effort, is supported by the General Services Administration, HUD, and other federal agencies concerned with telemedicine.

Over the last 15 years, Dr. Manson and his colleagues have acquired a research portfolio currently in excess of $44 million, drawing upon federal, state, private, and tribal sources, and involving collaboration with over 43 Indian and Native communities. He publishes extensively on the assessment, epidemiology, and prevention of physical, alcohol, drug, and mental disorders across the developmental life span of Indian and Native people. Dr. Manson is the founding editor of *American Indian and Alaska Native Mental Health Research*, a professionally refereed journal dedicated to this area of concern. He also serves on a wide range of boards and panels, including the National Institute of Mental Health, Office of the Surgeon General, Department of Veterans Affairs, Office of Technology Assessment, Institute of Medicine, State of Oregon Governor's Commission on Alcohol and Drugs, American Association of Retired Persons, Gerontological Society of America, and Denver Community Mental Health Commission. Dr. Manson has received numerous awards for his work, including the Colorado Public Health Association Researcher of the Year (1994), Beverly Visiting Professorship at the Clarke Institute of Psychiatry, University of Toronto (1995), the Indian Health Service's Distinguished Service Award (1996), the prestigious Rema Lapouse Mental Health Epidemiology Award from the American Public Health Association (1998), Walker-Ames Professorship at the University of Washington (1999-2000), and the Hammer Award from Vice President Gore (1999).

Velma Garcia Mason, Ph.D. (Acoma)

Dr. Mason is the Director for the Office of Alcohol and Substance Abuse Prevention in the Office of the Assistant Secretary of Indian Affairs, U.S. Department of the Interior, Washington, D.C. The office of Alcohol and Substance Abuse Prevention (OASAP) was established in 1986 by Public Law 99-570, the Indian Alcohol and Substance Abuse Prevention and Treatment Act. OASAP serves as the point of contact for the Assistant Secretary of Indian Affairs and the Bureau of Indian Affairs (BIA) with Indian tribes, other federal agencies and states on alcohol, substance abuse, and violence prevention initiatives, policy questions, or issues. Its mission is to assist tribes in decreasing the incidence and prevalence of alcohol and substance abuse on Indian lands, and it has an oversight function for BIA alcohol and substance abuse prevention-related activities, including those within BIA-funded schools, trial courts, law enforcement services, child protection/Social Services, highway safety, and tribal government.

Dr. Mason is from the Acoma Tribe in New Mexico and has two grown children and four grandchildren.

Dr. Mason has over 30 years of inter-disciplinary experience in alcohol and substance abuse prevention including research, evaluation, education, policy development, management, and administration. She was the former Director of OASAP from 1993 through 1995, first Director for the National Indian Drug Abuse Study at Colorado State University from 1972-1978, and later served on the faculty at American University in Washington, D.C., as a Research Assistant Professor and as a principal investigator on a National Science Foundation grant to develop cross-cultural testing instruments for drug use research in collaboration with UCLA and Johns Hopkins University. During this period, she had also served as an ADAMHA consultant.

Dr. Mason also worked at the U.S. Department of Education from 1985-1993, as a BIA Agency Superintendent from 1995-1996, and at Acoma, New Mexico, as a Director for Intergovernmental Affairs for the Governor's office from 1996-1999, where she worked on tribal government development projects including self-governance, planning and development initiatives, legislation, and historical preservation. In 1969 and 1970, she worked as a tribal government operations specialist for the Bureau of Indian Affairs, where she created the Tribal Government Development Program and drafted the concept paper for the Indian Self Determination initiative. In 1967, she worked for the Indian Health Service as a Social Worker Associate at the Phoenix Indian Hospital. She also has taught at Pima College in Arizona, University of Arizona, University of New Mexico, Gonzaga University, Black Hills State College, and American University, and lectured at Cornell University, Michigan State University Law School, and Princeton University. She also worked on the Kennedy Subcommittee on Indian Education study.

Dr. Mason received her Ph.D. in education foundations from the University of New Mexico, her B.A. degree in psychology and sociology from Mount Mercy College in Pittsburgh, Pennsylvania, and an M.A. degree in cultural anthropology and linguistics from the University of Arizona. Her scholarly interest focused on research in isolating predictive values of Native American cultural and language identity factors within self-concept acquisition and alcohol and substance abuse.

Joseph B. Stone, Ph.D., CAC Level III, ICADC (Blackfeet)

Dr. Joseph B. Stone is an enrolled member of the Blackfeet Tribe of Northern Montana. He currently resides in Sheridan, Oregon, where he is the Program Manager and Clinical Supervisor: Confederated Tribes of the Grande Ronde Behavioral Health Program (CTGR BHP). He owns and operates Kinuk Sisakta Consultation, Training, & Research Services. His grandparents, Joseph and Mary Stone, raised Joe on a ranch north of Cut Bank, Montana, where he grew to love the classical western life: riding, working cattle, and breaking horses.

In his early academic career Dr. Stone was dismissed for academic failure seven separate times from various colleges and universities. He has had various job experiences, including being an oil field roughneck, Montana logger, commercial cowboy and ranch-hand, construction worker, U.S. Navy electrician, and Hood Canal Floating Bridge Technician. In 1984, he returned to Montana and enrolled in the Montana State University (MSU) electrical engineering program.

It was at MSU that Joe's first academic interest, psychology, was reawakened. In 1990 he graduated from MSU with an undergraduate degree in home economics and non-teaching minor in psychology. At MSU, Joseph met Deanna, his wife and beloved life companion. They were married in the MSU Chapel in August of 1990. Joe and Deanna spent the next four years in Logan, Utah, where Joe completed the didactic portion of his clinical training. Deanna obtained a degree in English and Health Education. Following this, Joe and Deanna moved to Rapid City, South Dakota, for his internship at the Fort Meade Veteran's Affairs Hospital and Indian Health Service Regional Hospital (Sioux San).

Between 1995 and 2000, Joe was the Director: Lower Elwha Klallam Tribal Behavioral Health Program. He moved to Grand Ronde, Oregon, in 2000. Deanna recently earned an M.S.W. with a specialty in children and families from the University of Washington. Jerry (3 years) & Jessie (2 years) joined the family in 2001. Taj is Jerry's dog & Sigmund is Joe's dog. Jessie has not yet been gifted with a critter.

Joseph's clinical and research interests are in the areas of assessment and treatment of child physical and sexual abuse, dual diagnosis of behavioral health and substance abuse disorders, addictive behaviors, and post-colonial stress. Joseph is an avid hobbyist, who would rather play foosball, but who wouldn't, and also enjoys shooting hi-powered pistols and listening to the blues. He is equally comfortable with modern western society or "rez" life. The iniupi or sweat lodge is Joe's current favorite form of self and family healing practice.

Oral presentations and discussions are a greater passion and interest than writing at this point. Joseph regards learning more as a product of social interaction than as a product of lecture. He always walks away from leading an academic discussion feeling like he learned more than he taught and when this enjoyable part of the "teaching" process ceases, Joseph will stop "teaching." Hearty interaction and participation is strongly encouraged, so come to Joe's training session equally prepared to share and teach as much as you are prepared to learn. But, remember, some of us participate silently, by listening with respect and interest: this is a fully acceptable way of being present.

About the Facilitator

Holly Echo-Hawk, M.S. (Pawnee-Otoe)

Holly Echo-Hawk (Pawnee-Otoe) is the founder of Echo-Hawk & Associates, an organizational behavior and management consulting firm specializing in the field of children's mental health. Born and raised in Pawnee, Oklahoma, Holly comes from a strong family well known for their commitment to social justice and tribal rights. She was also blessed to have loving and concerned parents who were devoted to their marriage and their children until their untimely deaths at ages 42 and 43.

Holly attended Pawnee schools, Chilocco Indian School, the University of Oklahoma, and the University of Texas, where she received her bachelor's degree in American studies. Tragedy struck Holly again when she was widowed in 1982, leaving her with her then 3-year old son. Following the death of her husband, Holly completed her master's degree in organizational behavior at the California School of Psychology in Berkeley, California, as a way to ensure that she could give her son the opportunities in life that every child deserves. Holly has always cared about children and has made this her life's work. Drawing on her life experiences and her belief that out of tragedy comes great strength, she started her work in juvenile justice 25 years ago in an urban Indian OJJDP program. Her job was to extract Indian youth from the juvenile jails and court systems in the San Francisco Bay Area, and prevent their return through counseling and support. Wanting to have a broader impact on services to children and youth, she later turned to the administration of children's programs.

During the past 20 years, Holly has served as the executive director of three child and youth service organizations. Her last non-profit position was as a vice president of a 100-year old child welfare and children's mental health organization. In this role, she was responsible for services ranging from therapeutic group care for child sex offenders to leadership development for minority youth.

In addition to her work in the field of child and family services, Holly is a 3-time governor appointee to the board of trustees of Clark College. Just completing a decade of service as one of five trustees of Clark College, Holly has provided vision and stewardship for the college which, with a $33 million annual operating budget and a $45 million private college foundation, is one of the largest college foundations in the country.

Today, Holly is the owner of Echo-Hawk & Associates, an organizational behavior and management company specializing in children's mental health transformation work. Echo-Hawk & Associates' most recent work has been with the National Indian Child Welfare Association, Georgetown University, the Child, Adolescent and Family Branch of the SAMHSA Center for Mental Health Services, as well as with mainstream child welfare organizations. She is frequently asked to facilitate national policy discussions on a range of topics and is able to bring both humor and a local perspective to the discussion at hand. Holly has worked with numerous tribal programs across the country and is the co-author of two monographs, *Cultural Strengths and Challenges in Implementing a System of Care Model in American Indian Communities* and the soon to be published monograph titled *The Role of Traditional Practices in Native American Mental Health.*

Holly lives on three acres outside of Vancouver, Washington, with her husband and 10-year old stepson. Her 19-year old son recently moved into his first apartment in Eugene, Oregon.

Appendices

APPENDIX A

Work Group on
American Indian Research Program Evalulation and Methodology
(AIRPEM)
Symposium on Research and Evaluation Methodology:
Lifespan Issues Related to
American Indians/Alaska Natives with Disabilities
April 26-27, 2002
Washington, DC

Facilitator

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APPENDIX C

American Indian Research and Program Evaluation Methodology (AIRPEM) Symposium Chapter Review Coding Sheet

Section One: Chapter Demographics:

Chapter Authors / Researchers:

Chapter Title:

Year: Volume: Pages:

Chapter Sequence of Review:

Date of Review:

Chapter Reviewer:

Section Two: Discussion of Post-Colonial Issues Impact on the Research/Evaluation:

A.) Post-Colonialism (stress) clearly defined as a construct of interest and impact to critique and discussion of the research or evaluation:

1.) Yes:_____

2.) No:_____

a.) The Post-Colonial (stress) construct or definition as used in the critique and discussion of the evaluation or research:

B.) The Post-Colonialism (stress) construct is acknowledged and used within the construction of the critique and discussion of the research and evaluation, but is not implicitly defined:

1.) Yes: _____

2.) No: _____

a.) How the Post-Colonial (stress) construct emerges or is constructed in the critique and discussion of the evaluation or research:

C.) The relationship of Post-Colonialism (stress) to research and evaluation and the complications acknowledging this construct introduces into designing evaluation and research is acknowledged and discussed:

1.) Yes: _____

2.) No: _____

a.) Intergenerational effects _____

b.) Intergenerational trauma _____

c.) Intergenerational unresolved grief _____

d.) The duration and pervasiveness of adversity _____

e.) Intergenerational effects

i.) Underestimated _____
ii.) Overestimated _____
iii.) Accurately estimated _____
iv.) Not estimated _____

f.) Resiliency and impact on research and evaluation

i.) Not discussed _____

ii.) Discussed _____

iia.) Underestimated _____
iib.) Overestimated _____
iic.) Accurately estimated _____
iid.) Not estimated _____

g.) Diversity between tribes and impact on evaluation and research

i.) Not discussed _____

ii.) Discussed _____

iia.) Underestimated _____
iib.) Overestimated _____
iic.) Accurately estimated _____
iid.) Not estimated _____

h.) The issue of the impact of prolonged or complex trauma on psychosocial functioning and the possibility that the sequelae of trauma that occurs over a prolonged period and encompasses all of individual, family, or communities experiences and might correlate with disability as a derivative or co-morbidity of Post-Colonialism (stress), per se; a disorder of extreme stress not otherwise specified (DESNOS) (Herman, 1992).

1.) Yes _____.

2.) No ____

i.) If discussed, how are the impacts of prolonged or complex trauma on the presentation of disability defined and addressed:

j.) If discussed, how is the relationship between research and evaluation and Post-Colonialism (stress) defined and addressed:

k.) If discussed, how is the issue of resiliency in research and evaluation and Post-Colonialism (stress) handled:

l.) If discussed, how is the issue of tribal diversity in evaluation and research and Post-Colonialism (stress) handled:

m.) Participatory action research and evaluation is discussed:

1.) Yes _____

2.) No _____

n.) If discussed, the implications of participatory action research and evaluation in the light of Post-Colonialism (stress) are defined:

Section Three: Results

A.) The chapter directly identifies and discusses how a Post-Colonialism (stress) theoretical perspective is combined with the methodological principles of participatory action research into a single model, Native American Post-Colonial Participatory Action Research (Fisher & Ball, 2002).

1.) Yes _____

2.) No _____

a.) The chapter points out how the evaluation and research project specifically uses, recommends, or implements specific replicable process mechanisms that are thought to be significant components of a Native American Post-Colonial Participatory Action Research Model:

i.) Tribal oversight _____

ia.) Tribal resolutions are obtained _____
ib.) Tribal oversight committees are used to guide the research and evaluation process _____
ic.) A tribal research code is developed and implemented _____

Discussion:

ii.) Tribal / community members are trained and employed as evaluation and research *project staff*

iia.) Yes _____

iib.) No _____

Discussion:

iii.) A tribal member is hired and used as a research and evaluation project facilitator:

iiia.) Yes _____

iiib.) No _____

Discussion:

iv.) Culturally specific intervention (research or evaluation) techniques specifically designed for that particular tribe or group of tribes are developed that respect and/or incorporate the cultural values of the tribe or group of tribes:

iva.) Yes, if the methodology is developed _____

ivb.) No, if the methodology is adapted _____

Discussion:

v.) Culturally appropriate alternative approaches to research design are developed and implemented:

va.) Yes _____

vb.) No _____

Discussion:

References

Fisher, P.A., & Ball, T. (2002). *Redefining the relationship between researchers and American Indian/Alaska Native communities: Native American postcolonial participatory action research.* Manuscript submitted for publication.

Herman, J.L. (1992). *Trauma and recovery.* New York, NY: Basic Books, Inc.

APPENDIX D

A Model for Conducting Research with American Indian Participants

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Published with permission of the author

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INTRODUCTION AND BACKGROUND

This document consists of a model for use by anyone intending to conduct psychological research with American Indian and Alaska Native people. It is intended to apply to both reservation and urban American Indian communities as appropriate. The words and their intentions represent the collective wisdom and experience of many years of hard work by American Indian and cross-culturally competent non-American Indian psychologists. This model was unanimously ratified by the full membership of the Society of Indian Psychologists at its annual meeting during June 1997 at the Utah State University Campus. This document is intended to be informative in nature and to inform potential researchers of all nations of the kinds of questions, obstacles, challenges, and important issues they must consider prior to engaging in psychological research with American Indian and Alaska Native people. The issues presented here are intended to act as a general model and are neither comprehensive nor entirely applicable to all tribes, clans, and family groups. Individual tribes, clans, family groups, or urban Indian communities may have additional requirements and issues requiring resolution prior to the initiation of such research.

Many important issues are presented as questions. The primary reason for this format is embedded within the notion that if a potential researcher cannot answer the question, that researcher should either: (a) not conduct the research or (b) involve someone (preferably a local American Indian psychologist) who can provide the appropriate amount of cross-cultural competency to the project. This model is presented with the intention that responsible and appropriate American Indian and Alaska Native mental health research is desperately needed, is an appropriate precursor toward establishing culturally appropriate treatments and community interventions, and is in the best interest of peoples of all nations.

GENERAL ISSUES FOR ANYONE CONSIDERING CONDUCTING RESEARCH WITH AMERICAN INDIAN PARTICIPANTS

1. American Indians have been misrepresented for 500 years. Take this into account!
2. More than 600 federally and state-recognized tribes exist in America, each with its own distinct oral history, tradition, and culture. Avoidance of unnecessary Pan-Indianism is therefore encouraged.
3. Not including tribal members or any American Indians in the development of the design, methodology, and information dissemination of research involving American Indian participants is a serious affront to those being studied and may very well invalidate any research "findings."
4. Cross-cultural competence in psychology training, research, and treatment is as significant an area of professional expertise as any other (i.e., neuropsychology, pediatric, etc.). Competence is established through supervised training and experience. Prospective non-American Indian mental health researchers must ask themselves if they truly have it.

RESEARCH, DESIGN/QUESTION ISSUES, QUESTIONS TO EXPECT, AND COMMENTS

1. Why are you doing research with American Indian subjects? The old lines about the data being good for the population being studied and for the good of the field of psychology and "science," etc., are no longer good enough. A researcher should have a well-considered answer. For example: "Many people are questioning whether or not there are significant differences between diabetes prevention behaviors of your tribal members and non-tribal members living off the reservation. Having access to this data could allow the tribe to develop diabetes prevention programs through the Indian Health Service, the

State, or other funding agencies. But we won't know for sure until we have some data resulting from careful, responsible research."

2. What impact, positive or negative, is your study going to have on this tribe/urban American Indian community? Are there direct benefits or risks, such as funding gain or loss, public relations (PR), or perceptual gains or losses, such as reinforcement of "American Indian" stereotypes?
3. Is the research question/hypothesis culturally relevant, sensitive, and appropriate? If the answer is "I don't know"—quit, or get a significant American Indian consult. In essence, if the principal investigator of a research project does not know the answer to this question, he or she is not cross-culturally competent enough to conduct the project and should either discontinue it or involve others who can help.

METHODOLOGY ISSUES/CONSIDERATIONS

1. Instrumentation selection. This is a sensitive/controversial topic in Indian Country. In general, one must consider the appropriateness of using psychological tests that lack sufficient standardization on or with American Indians. Specific issues:
   a. Test development issues
      (1) Authors: Who were the authors? Were they culturally competent?
      (2) Item generation: What approach was used? Was an American Indian focus group used in the item-generation or prototype development process?
      (3) Standardization: On how many American Indian subjects was this test normed? What tribes or urban American Indian communities were represented and from what economic strata? Was subject biculturalism taken into account?
   b. Psychometrics. Which of the following have been statistically determined for using this test with American Indian subjects?
      (1) Validity (cultural, content, construct, criterion)
      (2) Reliability (test-retest, internal, alternate forms)
   c. Cultural sensitivity/appropriateness. Some subjects/topics are strictly off-limits or completely irrelevant with some tribes or individuals, while others are acceptable. Is your instrument sufficiently informed by/equipped with this knowledge?
   d. Language usage/level. Is the language usage/level appropriate for use with the proposed subjects? Most instruments are not. Many exhibit reading levels and vocabulary that are either too high or difficult for bilingual speakers.
   e. Length. Is the instrument too long? Most are. If so, you will lose information and subjects. Many investigators make the mistake of abusing their research opportunity by piling on multiple and lengthy instruments. Others are too preoccupied with the mindset that more items and multiple measures will increase variance, statistical robustness, and psychometric power. Although this may be true, it also causes excessively high subject mortality among American Indian subjects, either torpedoing the entire effort or forcing overreliance upon the dangerously small sample size that remains. Two suggestions:
      (1) Don't be greedy, and (2) make brevity and conciseness high priorities. For example, if two potential instruments are equally usable, culturally appropriate, etc., select the shorter of the two.

2. Subjects/participants. Following are issues and questions about the sample to consider prior to conducting the research effort.
   a. Why American Indians, why these American Indians, and how will we benefit? Potential researchers need to have good, informed, respectful answers to these questions if they wish permission to proceed.
   b. Local human subjects committees/institutional review boards: Researchers should secure permission from local tribal or urban American Indian community human subjects committees, tribal councils, cultural committees, tribal college research departments, or another designated agency/group for permission to proceed. Without permission, do not proceed!
   c. Sample size issues
      (1) How many is "enough?" Why? Be prepared for small sample sizes, both statistically and logistically. Some tribes/urban American Indian communities only have one or two thousand residents from which to draw a sample.
      (2) Researchers should take the small size of the sample into account in data interpretation—use extreme care: It is important to consider that researchers may be dealing with a population, and not a sample. This idea is reinforced by the concept that each tribe is a distinct cultural and ethnic entity.
      (3) Sample size: The population is seldom all American Indian people on this continent (although it is conceivable that some Pan-Indian designs might be appropriate—as a rule of thumb, they are not). More commonly, the population in question may indeed consist only of the members of one tribe, and some tribes are small. Therefore,

small sample sizes in terms of numbers may actually be high representation in terms of percentage of available subjects from a given population.

d. Representation: Aside from sample size, how adequately does the sample represent the clan/family group, the tribe/community, and all American Indian people?
   (1) "Pan-Indianism": Is this your goal, or a serious design/methodological/ interpretive error? Be informed and have the answer a priori.
   (2) SES stratification: To what degree does SES affect your domain of study with these American Indian subjects? Have you considered "class" effects?
   (3) Geographical representation (reservation research): Some clans/family groups cluster together in certain areas. Many hold certain vales [*sic (values)*] and beliefs that may vary slightly, yet significantly, from that of other clans of [*sic (or)*] family groups within the same tribe. These subtle differences often translate into behavioral differences. How will your study account for these differences or similarities?
   (4) Racial issues (i.e., blood quantum): Race is never a valid predictor of anything non-physiological, particularly cultural ethnic values and related behaviors. "Traditional" American Indians are of many blood quantum levels. Studies that establish race as a significant independent variable can anticipate a great deal of controversy and interpretive difficulty, given the complexity and sensitivity of this issue.
   (5) Control or comparison group designs: If you are using control groups, be sure they are equivalent in all respects to your experimental group. This is difficult to do, for most of the reasons already stated.
   (6) Biculturalism/acculturation levels: Study designs must take bicultural competence into account. Reservations and urban American Indian communities are diverse in many ways, most notable [*sic*] in the degree to which their members are culturally knowledgeable and practiced in the value systems, norms, and behaviors of both their native and the majority cultures. The degree of cultural competence in both or either will significantly affect perception of environmental stimuli (including all the values, emotions, and beliefs that go along with it), and ultimately, behavior.

3. Procedures and related issues.
   a. Local contacts are vital. Make sure you use the local talent in collecting data, making contacts, etc., as reputation is everything in American Indian communities. Make sure your confederates/assistants have good contacts because this may affect subject participation.
   b. Conduct data collection procedures in an appropriate way.
   c. Respect: Show proper respect to elders, children, physically and mentally handicapped people, and tribal officials.

This article was printed along with other suggestions regarding research with diverse groups in APA's "Guidelines for Research in Ethnic Minority Communities" by the Council of National Psychological Association[s] for the Advancement of Ethnic Minority Interests (CNPAAEMI).

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